

Planning for the Future
A Comparative Study of Advance
Directives in Scotland, England and
the Netherlands

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Doctor of Philosophy
The University of Edinburgh
2004



Declaration

**This thesis and the research described within have
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**It has not been previously submitted for a degree at
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31 December 2004

Abstract of Thesis

This thesis comprises three comparative case studies of advance directives under existing legislative arrangements in the Netherlands, Scotland and England. In the Netherlands, an Act of Parliament gives statutory backing to advance directives. In Scotland, the principles of the Adults with Incapacity (Scotland) Act 2000 instructs persons who take any intervention under the Act to have regard to a person's previously expressed wishes. Whereas, in England, no current statute governs medical decision-making and practitioners look to the common law for legal guidance. The research seeks to elucidate attitudes to advance directives within the medical and legal professions in each country and to determine how much impact (if any) they have on treatment decision-making for incapacitated persons. It focuses on the process of medical decision-making for patients with and without capacity, and the ways in which medical and legal professionals assess the adequacy of existing arrangements. The primary goals of the thesis are to understand whether, and if so how, advance directives contribute to patient autonomy, the extent to which legal regulation controls medical decision-making, and the effects of advance directives on the balance of power between doctors and patients. Two models of decision-making ('substituted judgement' and 'best interests') and how doctors use them to make decisions for persons without capacity are considered.

Arguments in favour of advance directives are usually based on the principle of respect for individual autonomy, and the belief that anticipatory decision-making provides a mechanism for preserving patients' autonomy when they are no longer capable of expressing their own preferences. The idea of using anticipatory decision-making as a method of extending individual autonomy into the future has been welcomed by the majority of medical and legal professionals. However, a significant minority express serious doubts about the efficacy of advance directives in preserving the autonomy of the patient, especially when this conflicts with the doctor's professional autonomy and the exercise of the doctor's professional power. They may erode the ultimate decision-making power of the doctor and exacerbate the conflict between individual and professional autonomy. Professional autonomy stems not only from the doctors' knowledge and expertise but also from their position as

gatekeepers for goods and services; it is protected by the medical profession's right to self-regulation which enables doctors to define both the needs of patients and how these needs should be met.

The study uses a socio-legal approach based on fieldwork in the Netherlands, Scotland and England to study this important issue in medical law. Qualitative interviews were conducted with 10 lawyers and 10 doctors in each country and interview data were analysed using NVIVO. The data were used to study advance directives in relation to medical decision-making, individual and professional autonomy and the balance of power between doctor and patient. The main findings are that, in all three countries, advance directives can be significant in protecting patient autonomy and can be used to strengthen the patient's substituted judgement. Statutory regulation of advance directives (in the Netherlands) does not appear to protect patients' autonomy any more than the common law (in Scotland and England); in fact the common law seems to be marginally better at ensuring incapacitated patients' rights to their own choices. Differences in legal regulation of advance directives in each country have made little difference to the inequality of power between doctor and patient but legislation is being used to initiate a reduction of that inequality in the Netherlands, where statutory regulation can strengthen the patient's substituted judgement and emphasise or enhance decisions made by a patient's representative. Power in both England and in Scotland is still heavily weighted on the side of the physician but, in England, advance directives can help relationships between doctor and patient where the act of writing an advance directive encourages patients to open a dialogue with their doctors and promote discussion of future treatment preferences. In Scotland, however, there has been little change in the doctor-patient relationship – it is still believed that 'doctor knows best' and prevailing opinion suggests that advance directives are not be legally binding on doctors.

The thesis makes a significant contribution to understanding the operation of advance directives and their impact on medical decision-making. By investigating medical decision making in three different jurisdictions, it shows that a patient's personal autonomy is tolerated rather than celebrated by those in possession of professional autonomy and power, regardless of the nature of the legal rules involved.

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Acknowledgements

The journey has not been an easy one, but at last the end is in sight and I would like to express my thanks to the many people who have helped me along the way. First of all I would like to thank my supervisors Professor Mike Adler and Dr Graeme Laurie. Dr Laurie has been a great source of help and advice in the area of medical law, and Professor Adler has provided a great deal of support and encouragement over the course of this PhD and my MSc. When things got difficult he was particularly inspiring and he rallied round with a sympathetic ear and welcome words of advice.

I would like to thank all my friends in the Graduate School who have been a continual source of encouragement and lively debate. Moreover they were always available for commiseration and congratulations over good food and wine. Thanks to all of you, especially, Marsha, Sue K., Cameron P., Richard, Sally, Kathryn, Jackie, Julia, Donna, Paul, Audrey *et al.* Apologies to those of you not mentioned, but thanks anyway, you know who you are. Thanks too go to colleagues at CRFR, especially Liz and Rachel, and to friends and colleagues elsewhere, Debs, Nina, Euan and Ann G.

Finally, I would like to thank my long-suffering family who have stood by me despite the tears, tantrums and soul searching over the past four years. Love and appreciation go to my husband Robbie and all the boys, Jamie, Mac, Elliot and Mac, you never doubted in my abilities even when I couldn't see the light at the end of the tunnel. There is no way that I could have done this without you all.

List of Abbreviations

AD	Advance Directive
AS	Advance Statement
AWI	Adults with Incapacity
BMA	British Medical Association
CARE	Christian Action on Research and Ethics
CDJC	European Committee on Legal Co-operation
CEAG	Clinical Ethics Advisory Group
CPR	Cardio-Pulmonary Resuscitation
CPSO	College of Physicians and Surgeons of Ontario
CT Scan	Computerised Tomography Scan
CVA	Cerebrovascular Accident
DD	Dutch Doctor
DL	Dutch Lawyer
DNR	Do Not Resuscitate
DoH	Department of Health
EC	European Commission
ECHR	European Convention for Human Rights and Fundamental Freedoms
ECJ	European Court of Justice
ED	English Doctor
EL	English Lawyer
EU	European Union
FATE	Friends at the End
GMC	General Medical Council
GP	General Practitioner
ITU	Intensive Therapy Unit
KNMG	Royal Dutch Medical Association
LC	Law Commission
LCD	Lord Chancellor's Department
MORI	Market and Opinion Research International
MR	Master of the Rolls

MSP	Member of the Scottish Parliament
NAO	National Audit Office
NHS	National Health Service
NVVE	Dutch Euthanasia Society
ONS	Office for National statistics
PEG	Percutaneous Endoscopic Gastrostomy
BOPZ	Mental Health Law
PVS	Permanent Vegetative State
RCN	Royal College of Nursing
SAMH	Scottish Association of Mental Health
SD	Scottish Doctor
SL	Scottish Lawyer
SLC	Scottish Law Commission
UK	United Kingdom
VES	Voluntary Euthanasia Society
VES	Voluntary Euthanasia Society
VESS/EXIT	Voluntary Euthanasia Society of Scotland
WGBO	Law on Contracts for Medical Treatment
WMA	World Medical Association

GLOSSARY OF DUTCH TERMS

<i>DUTCH</i>	<i>ENGLISH</i>
Duitse	German
Geneeskunde	Medicine
Gezondheid	Health
Gezondheidsrecht	Health law
Gezondheidszorg	Healthcare
Letselschade	Personal Injury
Levenstestament	Living will
Meerderjarige	Of age
Mensen	People
Onbekwame	Incompetent
Plaats	Place, situation
Tijdschrift	Magazine, journal, review
Vereniging	Society
Vertegenwoordiger	Representative
Voorbeeld	Example, model
Wet bopz	Special Admission to Psychiatric Hospitals Act 1994
Wettelijk	Legal

Chapter One Introduction to the Thesis

Introduction

This introductory chapter covers several areas. Firstly, there is a brief historical account and definition of advance directives; secondly, a broad outline of what this research is about and what it hopes to achieve. Next, the existing legislative arrangements for advance directives in the three countries - the Netherlands, Scotland, and England - are explained. As this study is based in Europe, there is also a brief account of the European perspective where it is useful to this thesis. The final part of the chapter discusses advance directives and their place in the current debate on euthanasia. This is necessary because, while this research is not concerned with euthanasia *per se*, it would be wrong to ignore this important issue in the discussion of advance directives

Advance Directives – The Background

New York State Judge Benjamin Cardozo held in 1914 that ‘every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without the patient’s consent commits an assault’ (*Schloendorff v. Society of New York Hospitals* 211 NY 125; 105 NE 92 (NY, 1914)). This is the basis for medical consent to treatment issues within most of the Western world and it follows that, while a patient cannot validly consent to treatment designed to kill him or her, any competent adult can refuse consent to any form of medical treatment regardless of the consequences (*Re T* [1992] 4 All ER 649). This legal recognition of the principle of autonomy and the consequent right of self-determination is further illustrated in the rulings of two leading appeal cases.

The House of Lords in *Bland* established that:

... the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so ... [t]o this extent, the principle of the sanctity of human life must yield to the principle of self-determination ... (*Airedale NHS Trust v. Bland* [1993] 1 All ER 821 *per* Lord Goff of Chievely at 864)

Similarly the Court of Session in Scotland:

Where the patient is of full age and capable of understanding and consenting to the procedures which on medical advice are for his or her benefit, or decides to refuse treatment, the right of self-determination provides the solution to all problems, at least so far as the court is concerned. It is not in doubt that a medical practitioner who acts or omits to act with the consent of his patient requires no sanction or other authority from the court. The patient's consent renders lawful that which would otherwise be unlawful (*Law Hospital v. Lord Advocate* 1996 SLT 848 *per* Lord President Hope at 852F).

Problems arise when the person no longer has the capacity to give his or her consent to or refusal of medical treatment. In 1969, a Chicago lawyer, Luis Kutner, invented the living will, a document that, when 'adjudicated by a court and buttressed by medical and lay testimony and evidence, can create the affirmative inaction termination of a patient's life' (Kutner, 1969: 554). It is a means by which individuals can provide, in advance, evidence to rebut the presumption that life-prolonging treatment can be given to them when they are unable to decide for themselves (Sommerville, 1996a: 32). In 1976, Karen Quinlan, a patient diagnosed as being in a persistent vegetative state, inspired the first state law granting legal status to living wills in America (California Natural Death Act 1976). Subsequently, most states have passed legislation that allows patients to die "naturally". In Britain we do not have any such legislation; The Medical Treatment (Advance Directives) Bill was introduced by Lord Allen in 1992, and would have given advance directives legal status, albeit with certain qualifications, but it was unsuccessful.

The generic term "advance statement" encompasses a variety of forms of prospective decision-making and can be known as an advance directive, advance refusal or living will. They all have one thing in common - they allow the declarant to make his or her wishes known in relation to any medical treatment in case of his or her incapacity to

give instructions (Hanafin, 1997: 80). They can declare the circumstances in which any life-sustaining treatment may be stopped (Brazier, 1992: 457), and give instructions regarding the patient's values and goals and choice of treatment (Post, 1999: 37). Often formal, written documents, they would probably be admissible as valid evidence in any subsequent decisions of the patient's "best interests".

The person making the directive may specify the treatment he or she does or does not want under certain conditions. This is often referred to as a "treatment directive" and may have either positive or negative characteristics. A negative directive would specify those treatments the person would not wish to receive in specified circumstances. A positive directive, on the other hand, would give instructions to healthcare providers regarding life-prolonging treatment (resuscitation) or life-shortening treatment (euthanasia) that the person wished to be given in specified conditions. Since futile treatment is unlikely to be given, 'the legal significance of positive directives is therefore very limited in nearly all jurisdictions' (Vezzoni, 2001: 72). The only country, which gives legal status to positive treatment directives, is the Netherlands. The recent law legalising euthanasia¹, under certain conditions, permits a person to ask for euthanasia in an advance directive.

In some jurisdictions, the law recognising advance directives, *requires* that medical practitioners *must* follow a valid directive; these so-called 'rules' can form the basis of binding directives. Licensing directives have accompanying 'may rules' which *allow* practitioners to follow patients' wishes set out in advance directives. This legal recognition affords protection to medical practitioners against possible civil or penal sanctions when the death of patient results from following an advance directive (*ibid.*). In the three countries in this study (Scotland, England and the Netherlands) the legal status of advance directives is strong. The legal rules designed to protect the patient's autonomy in situations of incapacity are generally binding on doctors. All have some degree of 'must rules' accorded to advance directives with varying degrees of limitations varying from a small number in the Netherlands to an middling amount in Scotland and England, meaning that the instructions in valid treatment directives must be respected (*ibid.*).

¹ The Termination of Life on Request Act 2001

A proxy directive differs from a living will or advance directive. It does not set down specifics in relation to medical treatment, but rather it allows the person to appoint someone else to make these decisions on his or her behalf in the event of incapacity. If there is a living will formalised in written form, the drafter may name a proxy² to make these healthcare decisions (Hanafin, 1997: 80). In these circumstances, the two directives can be complementary.

An advance directive can be 'a written document, a witnessed oral statement, a signed printed card, a smart card or a note of a discussion recorded in the patient's file (BMA, 1995a: 4). Directives need not be written to be valid: the individual may have discussed his or her wishes with a doctor, nurse or close relative before becoming unable to express his or her wishes personally. If this has been recorded in the patient's case notes, 'this will have the same status as a written advance directive' (1999: 15).

Oral statements to family members, friends, and health care professionals are the most common form of advance directive. However, oral statements are problematic if they are vague and ambiguous or if they were casual comments rather than seriously-intended directives. When an advance directive results from a conversation between two people it is not possible for a doctor to know whether the conversation between them was the only conversation the relevant individual had on that subject. There could have been others in which that individual might have expressed different opinions about whether he or she would or would not wish to receive certain treatment. Often people do not know what medical advice and assistance might be available to them in a given set of circumstances and unless the decision has been discussed with a doctor who has some knowledge of the individual's circumstances, the individual will not know whether the decision is in his or her best interests (House of Commons Standing Committee A, 2003: Column Number: 208). This

² The term 'proxy' refers to any person who has authority to act on another's behalf. It is probably best known in relation to voting by proxy - the authorisation that a member of the electorate can give to another to exercise his/her vote in his/her absence.

may have implications for the status of oral advance statements in relation to the requirement of informed consent. The BMA guidelines state that

A conscious, mentally competent adult cannot be given treatment without his or her valid consent. Consent may not be valid if insufficient relevant information is given. It is illegal and unethical to treat an adult who is capable of understanding and willing to know, unless the nature of the procedure, its purpose and implications have been explained and that person's agreement obtained (BMA, 1999: para 4.1.1).

In the UK, the BMA states that, although oral statements are equally valid if supported by appropriate evidence, there are advantages to recording general views and firm decisions in writing. Advance statements are aids to, rather than substitutes for, open dialogue between patients and health professionals. Opportunistic or casual remarks by a healthy person that reflect distaste for life-prolonging treatment in the hypothetical event of incapacity are unlikely to meet the evidential requirements necessary to establish that it was an informed and considered decision. A general expression of views cannot be accorded the same weight as a firm and well-informed decision. However, if oral remarks are representative of consistently-held values, they can contribute to an evaluation of the patient's interests; if witnessed and made by an informed individual, they can carry legal weight (*ibid*, para 6.1).

Oral advance directives (verbal directives) can be allowed if there is clear and convincing evidence that they represent the patient's wishes. This can include evidence that the patient made the statement consistently and seriously over time, that it specifically addresses the actual condition of the patient, and is consistent with values that apply to other areas of the patient's life (Ramsay and Mitty, 2003). National Health Service policy guidelines for hospitals in England state that, where a patient has made an oral advance directive, there must be very clear evidence in existence which satisfies the consultant that the advance directive made orally is valid and can be acted upon. The policy states:

Some patients choose to express their wishes in a written document (an advance directive or "living will") but it is not necessary for the refusal to be in writing in order to be valid. However, under these circumstances it would be wise to have the patient's verbal instructions witnessed and confirmed in writing (Nolan 2004: para 3.4).

According to some medical practitioners, the effects of an advance refusal are much more serious than provisions in most testamentary wills, and for such a document to be legally enforceable, it should be properly signed and witnessed at least to the same standard of proof as a will. One, at least, of the witnesses should be required to certify to the capacity of the testator at the time of signing. Some practitioners find oral advance statements ethically unsound (Guild of Catholic Doctors, 1999) and therefore conclude that they should not be legally binding:

Oral advance directives, as opposed to contemporaneous decisions, given the circumstances in which they might be made and the risk of misrepresentation, should only be acceptable as a general indication of the patient's wishes, and not legally binding (Law Commission, Part V, 5.22).

There are no specific legal requirements concerning the format of advance statements in any of the jurisdictions studied. The minimum requirements for the statement to be legally valid concern only the individual's competence, awareness of the implications of the decision and the relevance of the decision to the circumstances which arise. The BMA believes that some people have a false impression that a written, witnessed statement carries more weight than their contemporaneous oral consent or refusal and so make statements for the wrong reasons. It follows that, 'health professionals must be aware of this and make all reasonable efforts to prevent such misunderstanding' (BMA, 1999: para 6.2).

Aims of the Research

My MSc dissertation (Anderson, 2000) involved an examination of the reasons behind the decisions not give advance directives legislative status by drawing on Lukes' (1974) one and two-dimensional views of power. In an analysis of English and Scottish documents, I sought to demonstrate how ideas have developed and changed in the process of consultation. I also conducted interviews with the Scottish Law Commission, the Scottish Executive, lobbyists, and religious groups, some of whom were opposed to and others were in favour of legislation. Due to constraints of time it was not possible to conduct interviews in both countries. I therefore adopted a two-tiered approach involving documentary analysis in England and Scotland and

interviews in Scotland only. This research builds upon my MSc dissertation and seeks to discover the attitudes to advance directives within the legal and medical professions under current legislative arrangements, and how much influence (if any) advance directives have in decision-making related to treatment for incapacitated persons.

Discussion of living wills focuses on the moral principle of respect for autonomy. Vernon (1996) acknowledges that medical treatment often occurs without moral difficulty and 'doctors usually take clinical decision making for granted' (*ibid.* 604). He sees anticipatory decisions as providing a mechanism for preserving patients' autonomy when they are incapable of making their own judgments and believes that the 'living will, when properly drawn up and executed, is perhaps the best device available to ensure respect for prior autonomy' (*ibid.* 605). Advance directives have raised serious questions of autonomy in the medical, nursing and medico-legal fields and the notion of using anticipatory decision-making as a method of extending personal autonomy into the future has been welcomed by the majority of healthcare and legal professions. However, a significant minority has serious doubts as to the efficacy of the advance directive in preserving individual autonomy, especially where this may conflict with the doctor's professional autonomy and inherent professional power.

My interest in this subject has its foundations in my nursing career. I encountered many patients and families who felt disempowered by their lack of knowledge and their ability to assert their wishes and I became interested in ways in which persons could retain some personal autonomy. Much decision-making concerning treatment for persons who have lost the capacity to give or refuse consent takes place without any clear understanding of those persons' wishes, and a statement made by the patient setting out what he or she would wish to consent to may be a way of preserving the patient's autonomy. However, following a document that sets out these wishes may erode the ultimate decision-making power of the physician and this may entail conflict between professional and individual autonomy. My earlier research provided an insight into the policy process involved in decision-making for incapacitated adults, and as such provides a useful background to this research which

focuses on the decision-makers themselves, i.e. on medical practitioners, patient, and their legal representatives; and exploring the process of decision-making concerning medical treatment for patients without capacity, how advance directives may be involved in this decision-making process and the ways in which those most involved assess the adequacy of the present legal arrangements.

This research aims to answer the following questions:

1. How is medical decision-making carried out, and how does this relate to statute or common law provisions in the three jurisdictions?
2. What are the processes of treatment decision-making for *incapax* patients and how are they related to doctors' professional autonomy?
3. How do doctors and lawyers view the current legal status of advance directives in each of the jurisdictions?
4. Do doctors consider advance directives when making treatment decisions for *incapax* patients?
5. How do advance directives affect professional and patient autonomy and the balance of power between doctor and patient?

In order to accomplish these objectives research was carried out in three locations: The Netherlands, Scotland, and England. In the Netherlands legislation may give a statutory basis to advance directives. In Scotland recent legislation (The Adults with Incapacity (Scotland) Act 2000) has deliberately avoided giving advance directives a statutory basis, but section 1(1)(a) of the Act implies some sort of legislative standing for advance directives. In England legality of advance statements is based on common law but the newly formed Department of Constitutional Affairs has published the Mental Capacity Bill which contains proposals to establish a legislative basis for advance statements³. These differing circumstances provide an ideal basis for comparison and the legal conditions in England and Wales and the Netherlands highlight the ambiguity of the nature of the Scottish legal situation. The legislative arrangements in each of the three jurisdictions investigated are detailed below, but a representation of their relationship can be explained in basic terms as a continuum, drawing attention to the lesser protection of the law in Scotland.

³ Published 26 June 2003

Legislative Arrangements and Advance Care Planning

Statute

Least **Greatest**
England & Wales ← **Scotland** → **The Netherlands**

1.1 Statutory law

Common Law

Least **Greatest**
The Netherlands ← **England & Wales** → **Scotland**

1.2 Common law

The Research Process

If social reality is whatever people believe it to be, the task of (social) science research is to describe people's perception of reality. This being the case, the interpretive paradigm, and thus valid knowledge, involves the researcher being able to accurately and plausibly document people's experiences, beliefs, meanings and so forth. Proof of valid knowledge, or epistemology, therefore, is based upon a researcher's ability to experience the world as others experience it and is usually - but not exclusively - gained by a researcher experiencing the world from the viewpoint of the people being researched. My experience within both the medical and legal fields is significant in this requirement of research.

This research employs a comparative case study strategy and seeks to develop an in-depth analysis of three cases using multiple sources – documents, case law, statutes, interviews, and personal narratives. The cases studied are the different legal jurisdictions examined, and the interviewees within each of the cases make up the data sources. Answers to my research questions are to be found in discussions with the appropriate persons within their professional roles; therefore, the information required will be best found through qualitative research methods within an interpretive perspective. The unique strengths of this method are situated in the context and setting of both the interviews and decision-making process; and facilitate

the 'search for a deeper understanding of how decisions [are] made by participants and their lived experiences of the phenomenon' (Marshall and Rossman, 1995: 39). By using in-depth interviewing, rich and varied data can be gathered (Bulmer, 1986) and questions about behaviour, what people think and feel, about beliefs and attitudes are some of the most beneficial uses of face-to-face interviews. The question 'what is the nature of reality' (Creswell, 1994: 5) will be answered through use of quotes and themes in the words of the participants, providing evidence of the differing perspectives concerned in this phenomenon. The research methodology employed in this research will be discussed in greater depth in chapter four.

Current Legal Situation

The Netherlands

In the Netherlands, the Law on Contracts for Medical Treatment (WGBO) 1995 introduced Part 5 (Medical Treatment Contracts), Articles 446-68 into the Civil Code; Article 450(3) concerns treatment directives and gives advance refusals of medical treatment legal force. The Dutch situation is almost unique in Europe, with only Belgium having somewhat analogous legislation, in that patients' rights are guaranteed by the legislature and regulated by contract law in the Civil Code.

Professor Jaap Rang first set out the aims of the patients' rights movement in 1973 in his inaugural lecture at Leiden University. This led the Dutch Government to ponder the question on how to implement these rights and two possibilities were suggested: the first was to leave it to the medical profession; the other was to introduce legislation. The former suggestion was rejected as legislation seemed more appropriate and the Government opted to use the civil law based on contractual obligations rather than the law of negligence.

The Act has certain advantages and disadvantages. Most authors agree that contract law is advantageous to all parties concerned but more heavily weighted on the side of the patient. Contract law is based on self-determination which is considered to be of fundamental importance in the relationship between doctor and patient. It is also based on party autonomy, the natural habitat of patients' rights, especially the right to

information, consent, and access to medical records. Use of contract law follows a tradition in continental Europe. The French, for instance, have always looked upon the relationship between doctor and patient as a contract and this tradition also exists in the Netherlands. It is a reciprocal contract agreement; but the emphasis is on strengthening the position of the patient. Strengthening of the position of the weaker partner in a civil contract (by specifying the contents of that contract) is in line with tradition Dutch law relating to, for example, workers and tenants (Merkenstein, 1995: 34).

The Act applies to the activities of doctors in relation to their patients and also to all contracts in which a healthcare provider undertakes to provide medical treatment. The healthcare provider can be either a natural or legal person e.g. a hospital; and this implies that a patient may have two contracts: one with the doctor for examination and treatment, and one with the hospital for nursing and care. This does not interfere with the relationship between doctor and patient. Medical treatment includes treatment by dentists, midwives and nursing staff; pharmacists are excluded.

The general principle underlying this law is that any medical treatment requires the informed consent of the patient. Doctors are now obliged to inform the patient clearly, and if necessary, in writing, about the proposed examination and treatment. In this respect Dutch law is now moving in the direction of German law, which developed the right of informed consent earlier (Nadorp-van der Borg, 1995: 1-13). But the right to be informed is not unlimited, Article 448 provides for a therapeutical exception, and under Article 449 the patient also has the right not to be informed.

In the case of incompetent patients the Act assigns the authority to consent to treatment to others. Their parents represent incompetent minors and Article 465 appoints the spouse or partner as proxy for incompetent adults. In their absence, other family members will be appointed. Many authors have expressed an aversion to family members acting as proxies (Leenan, 1988: 178-81; Gevers, 1987: 2094; van Veen, 1993: 6-10), but this will only be a problem if the patient has not made a treatment directive or appointed his or her own proxy. The proxy can take all decisions on the health care of the patient, but the Act provides that the healthcare

provider does not have to comply with the proxy's decisions insofar as they are incompatible with the level of care which a conscientious healthcare provider has to offer (Article 465(4)).

If the patient is no longer competent, refusal of consent can be found in a treatment directive or *levenstestament* (living will) written while the patient was still competent. Such a directive must be dated and signed, and the refusal has to be made in writing while the patient is still competent; there are no other formal requirements. The Act places a statutory duty on physicians to follow the patient's written instructions.

If a patient aged sixteen or over cannot be deemed capable of reasonably assessing his interests in the matter, the care provider and a person as referred to in paragraphs 2 or 3 of article 465 shall comply with the apparent opinion of the patient expressed in writing while he was still capable of the said reasonable assessment of his interests and containing a refusal to grant consent as referred to in the first paragraph. The care provider may deviate from this if he deems that there are well-founded reasons for so doing (Article 450(3)).

The age limitation for informed consent also applies in the case of the treatment directive: patients aged 16 years or older can give consent to (or refuse) treatment and patients between 12 and 16 years are presumed competent to make medical decisions, unless the contrary is shown. For minors under 16, the legal representatives (usually the parents) should be consulted, even if their consent is not required.

It took a lot of parliamentary pressure to get provisions for the legal status of advance statements into the WGBO. The amendment was made at the last moment, the main issue of the discussion being the value that can and should be attached to statements written in advance. The present provision is a compromise with very limited scope (Merkenstein, 1995: 37). The Dutch Parliament decided to enact legislation on this rather than leave it to self-regulation, i.e. to codes of conduct, professional guidelines drawn up by the medical profession, because the view was, that in the final analysis, legislation provides a right to self-determination in a way that self-regulation does not. While it is accepted that specific cases cannot be solved in advance by passing a

law, what can be done is to lay down general guidelines that create certain rules for healthcare providers and patients.

The treatment directive binds all care providers: if an incompetent person of sixteen years or older has in written form, clearly expressed opinions that contain a refusal of medical treatment, then the physician must follow these instructions. The law only allows deviation from it if 'there are good reasons to do so' (Article 450). The formulation is vague, but it is generally interpreted to refer to a well-founded doubt about the applicability of the directive to the current situation, or about the competence of the author at the time of writing the treatment directive. A common reason given for disregarding a treatment directive is that the request expressed no longer reflects the real wishes of the patient. To neutralise this argument, the Dutch Society for Voluntary Euthanasia (NVVE) suggests adding to any treatment directive a statement that the patient accepts this risk.

The Act provides for the patient to appoint a proxy who will take all decisions about the health care of the incompetent patient. This appointment must be made in writing while the person is still competent and above the age of majority (18 years) (Article 465(3)). The rights of the patient regarding medical treatment are transferred to the proxy, subject to some limitations. The proxy should behave as a 'good representative', trying to involve the patient as much as possible in the decisions, which should reflect the patient's wishes. When these are not clear, the proxy should decide on the basis of the best interests of the patient. If these requirements are not fulfilled, a care provider can refuse to comply with the decisions of the representative (Article 465(4)). The autonomy of the incompetent patient is further protected by the provision that, despite the consent to the proxy, a treatment cannot be performed if the patient strongly resists it. The only exception is if the treatment is necessary to prevent serious harm to the patients' health.

The patient cannot ask for euthanasia in the treatment directive, a separate document is required, and the doctor will not be allowed to perform euthanasia if the legal requirements are not met (Sutorius & Jansen, 1991: 994). It is generally accepted that a proxy cannot ask for euthanasia, unless there has been a clear request, in writing,

from the patient (Leenan, 1987: 2095). The Royal Dutch Medical Association (KNMG) has pointed out that it is important that such a written statement, in which the patient specifies his or her request for euthanasia, does not and should not imply a duty for the doctor to perform euthanasia. They state that ‘such advance directives will always remain imperfect instruments to state patients’ wishes ... [and] ... find it important that such documents have a high quality ... and should be updated on a regular basis’ (Markenstein, 2001).

As the WGBO is a matter of contract law, sanctions for infringements are civil (prospective and retrospective). However, a serious violation of the requirement of informed consent could give rise to penal or disciplinary sanctions, although Dutch courts see very few cases of this type (civil or criminal). Procedures are more likely to be heard in the Medical Disciplinary Tribunal (a legally established, public tribunal) but litigation (except for medical malpractice) against doctors and other healthcare providers is rarely practised in the Netherlands.

Scotland

The literature implies that advance directives may be legally binding in some fashion. Barr *et al.* (1994) devote seven pages to living wills and include a sample of a living will. It consists of two sections: Section A, an advance medical directive and section B, a “values history” statement. Within Section A there is the note ‘this section may be legally binding’ (*ibid.* 97). Lack of clarity surrounding the legality of advance directives may lead to vague statements of legality, such as this, leaving both healthcare professionals and the public unsure of the true legal status of advance directives.

In Scotland, prior to the Adults with Incapacity (Scotland) Act 2000, the tutor-dative⁴ may have been able to make treatment decisions on behalf of adults who lack decision-making capacity. Section 80 of the 2000 Act states that there will be no new appointments of tutors and Schedule 4 lays out the situation for tutors who were

⁴ A proxy decision-maker appointed by the Court of Session or the Sheriff Court with personal welfare powers only.

appointed before the Act came into force. Nevertheless, the validity of a treatment refusal⁵ has never been tested in the Scottish Courts. Such legal uncertainty was one of the reasons why the Scottish Law Commission included advance directives in The Report on Incapable Adults (SLC, 1995: para 5.41 ff.). The Commission recommended in Part 5 (medical matters) that doctors and other health care professionals should have a general statutory authority to treat incapable adults. However, decisions about consenting to future medical treatment were considered within the area of advance statements, which the Commission recommended to be put on a firm legal basis. The main reasons for the recommendation were:

- Legislation may clarify the position of doctors and would make it clear that a doctor who acts in good faith and with reasonable care, in accordance with an advance directive that he or she believes to be valid, should not be exposed to liability even if the directive is subsequently shown to be invalid.
- Advance statements are already recognised at common law in England and it is possible that the situation in Scotland is probably the same, but at present, the courts' role is limited to making declarations that a particular course of action is or is not lawful.

The Commission did not ignore the problems involved in taking this course of action and suggested that the main problems fell into three broad areas:

Firstly, there are dangers in relying on oral refusals:

- The doctor may not remember the precise terms of the refusal at the time when the treatment is being made;
- The oral statement may have been made to a person other than the treating doctor because of duty rotas, etc;
- Without some form of writing, even in the patients' case notes, it would be difficult to ensure that the treating doctors were aware of the terms of the oral advance refusal.

⁵ A patient cannot force a doctor to carry out treatment that is futile or unnecessary, but if the patient has capacity, he or she can refuse treatment regardless of the consequences of this refusal.

As a result of this, does an advance refusal have to be in writing and if so do any special formalities have to be observed?

- Undue formality and insistence on writing may deny effect to the wishes of the patient;
- Problems of construction may arise if a refusal referred to specified treatments for a particular condition but due to advances in medicine the doctors were proposing to use a different treatment.

Thirdly, there may be problems in following the directive:

- An advance refusal of treatment may involve a clash between the doctor's duty of care and the patient's own wishes;
- Some doctors tend to treat even if the treatment is futile for fear of being sued for negligence, or may have a conscientious objection to withholding life saving treatment;
- Undue influence by others might encourage the making of an advance refusal against their own will.

With these difficulties in mind, the Commission made the following recommendation:

Recommendation 68

- (1) Legislation should be introduced making it clear that, subject to certain exceptions dealt with in later recommendations, a valid refusal made by a competent patient of treatment that may be offered in the future when he or she is not mentally capable should have the effect that doctors have no authority to give the treatment in question.
- (2) Doctors should not be liable for withholding treatment in accordance with a refusal which they reasonably believe was validly made and is applicable in the circumstances, or for giving treatment contrary to the terms of a refusal that they reasonably believe is neither valid nor applicable.
- (3) A refusal should be effective whether it is in writing or oral. A written refusal should have to be signed by the patient but should not have to be witnessed or made in any particular form.

The recommendations were clarified by the following caveats:

- An advance refusal should have to apply to the treatment in question and to the circumstances in which the patient finds himself or herself before it is regarded as having binding effect.
- Drafting in more general terms could avoid problems regarding specific treatments and advances in medicine.
- The act of writing down an advance refusal focuses the patient's mind and helps the patient to set out the terms of the refusal in a more precise way.
- A clear and explicit refusal orally to a doctor in the presence of others should entitle legal effect to be given to such a refusal.
- Encouragement should be given to make the advance refusal in writing, simplified by a printed form in which blanks could be filled or boxes ticked.
- The Commission rejects the notion that doctors should regard advance refusals as advisory and simply take them into account in making treatment decisions as this gives too little weight to the principle of patient autonomy.
- The general authority of doctors to treat should not apply in the face of an advance refusal and therefore it follows that a doctor should be protected from any criminal, civil or disciplinary liability if he or she withheld treatment in accordance with an advance refusal.
- The assumption should be that the refusal was validly made by a patient with capacity to do so. Capacity is presumed so that the onus would be on those seeking to deny effect to the refusal to rebut the presumption.
- Undue influence on the patient should be an invalidating factor.

Following the Scottish Law Commission Report, the Scottish Office issued a Consultation Paper in 1997, requesting responses to the Commission's recommendations (Scottish Office, 1997). All the recommendations were accepted by the Scottish Office and set out in sections 6.25 to 6.32. The Consultation Paper specifically notes that 'respect for patient autonomy demands that an advance refusal of treatment made when capable, should survive any subsequent loss of capacity' (*ibid.* 1997: par. 6.27, p6). This concurs with the concept of autonomy stated in the English Law Commission's Papers.

Between the issue of the Consultation Paper and the collation of responses, the Scottish Parliament was created and it became evident that the Adults with Incapacity Bill would be its first major piece of legislation. The Justice Department supervised the Bill with input from the Health Department. As Part V was the most controversial area, the problem was how to make the contents and wording acceptable to the public. In response to questions regarding legalising advance statements there were 127 written responses with 72 against legislation, 31 in favour of legislation, and 24 that made no comment.

The strength of feeling by those who were opposed to legislation and the ambivalent reaction of proponents, combined with political considerations in such a high profile Bill, led the Executive to make the decision that would minimise conflict in the first year of the Scottish Parliament, i.e. to drop the issue of advance statements from the Bill. The issue did not disappear however, as advance statements had a re-assessment by the Millan Committee in the review of mental health legislation.

The Millan Committee was set up in 1999, to review the Mental Health (Scotland) Act 1984. It has published two major Consultation Papers, the first in April 1999 and the second in April 2000 (Millan Committee, 1999 & 2000), both Papers addressed the question of advance directives. The first consultation asked the following questions:

16.9 What are your views on the proposals in relation to advance refusals of treatment (Recommendations 68-74, SLC)?

16.10 What status (if any) should advance statements, or the views of guardians or welfare attorneys, have in relation to treatment carried out on a compulsory basis under mental health law?

In the second Consultation the Committee asked:

7.12 Do you think that advance directives should be binding unless the risks of a refusal would put the patient's life in danger or put others at risk? Or are there any other circumstances which would lead to them not being binding?

7.13 Alternatively, do you think advance directives should have no legislative status except for an expectation that they will be considered?

7.14 Or do you think advance directives should operate in some other fashion?

Again the views returned were polarised with extremes on both sides. Inevitably the decision of the review committee was to once more drop any explicit reference to advance statements in mental health legislation. In addition, while the Executive also withdrew explicit reference to advance statements from the Adults with Incapacity Bill; many organisations believed the general principles of the Bill (and now the Act) referred to advance statements in an implicit sense.

The Adults with Incapacity (Scotland) Act 2000 sets out the principles to be followed in interventions under the Act rather than a general test of what is in the best interests of the adult. Subsection (4) refers specifically to the adult's wishes. Subsection (4)(a) emphasises the importance of considering the adult's views, both those known to have been expressed in the past and their current views, regardless of their capacity (Explanatory Notes to the Adults with Incapacity (Scotland) Act 2000, 2000: 1). Within the general principles and fundamental definitions of the Act, section one states,

(4) In determining if an intervention is to be made and, if so, what intervention is to be made, account shall be taken of –

(a) the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication, whether human or by mechanical aid (whether of an interpretative nature or otherwise) appropriate to the adult;

The Act makes no reference to the “best interests” test, a concept that was developed in the context of the law on children. It is a general term and is considered more protective than is suitable for adults, as it would not give particular weight to the individual's own views, including those expressed previously while they had the capacity to do so. Laurie and Mason (2000) concur, viewing the ‘essentially paternalistic [“best interests” test] to be inappropriate when applied to adults’ (*ibid*, 176). They add that the concept of the welfare attorney⁶ to act as a proxy to be ...

... founded on the assumption that he or she is speaking “as” the incapax and is, thereby entitled to the same freedom to accept or refuse treatment as is enjoyed by the incapax – in other words, there is an intention, whether it is avowed or subconscious, to introduce the far more patient-orientated concept of “substituted-judgement” (*ibid*.)

⁶ Section 16 Adults with Incapacity (Scotland) Act 2000

In determining whether something should be done for an adult under the legislation subsections (4) (b), (c) and (d) AWI Act require that others must be consulted; those persons are:

(b) the views of the nearest relative and the primary carer of the adult, in so far as it is reasonable and practicable to do so;

the views of

- (i) any guardian, continuing attorney or welfare attorney of the adult who has powers relating to the proposed intervention; and
- (ii) any person whom the sheriff has directed to be consulted,

(c) in so far as it is reasonable and practicable to do so; and

(d) the views of any other person appearing to the person responsible for authorising or effecting the intervention to have an interest in the welfare of the adult or in the proposed intervention, where these views have been made known to the person responsible, in so far as it is reasonable and practicable to do so.

The nearest relative, primary carer, guardian, attorney and anyone nominated by the sheriff must be consulted by the decision-maker, so far as reasonable and practicable, for example so long as their whereabouts can fairly readily be ascertained. There is no obligation, however, to seek out the views of others who might have an interest, although if such views have been made known to the person taking the decision, they should be taken into account. As a consequence of these provisions, doctors making treatment decisions for adults with incapacity may find that they have to take a greater number of opinions into account.

But just how are the provisions of (4) (a) balanced against those of (4) (b) & (c)? In evidence to the Justice and Home Affairs Committee, the RCN pointed out that advance statements would be assumed to be expressions of past wishes and preferences of the adult. They warned that section 1 'will, in practice, result in enormous weight being attached to entirely unregulated living wills' (RCN, 1999: par. 8.2). The Royal College of Psychiatrists also believes that Section One will take account of advance statements. Their spokesperson said: 'I think that is where advance statements come in, so it is in there somewhere, but it is not given the prominence it had in the SLC report, it's implicit rather than explicit' (Dr Donnie Lyons, Royal College of Psychiatrists).

However, a key element of in Part 5 of the AWI Act is to introduce a 'general authority to treat' for medical practitioners responsible for the care of the incapacitated person. Section 47(1) states where the medical practitioner

(a) is of the opinion that the adult is incapable in relation to a decision about the medical treatment in question; and

(2) without prejudice to any authority conferred by any other enactment or rule of law, and subject to sections 49 and 50 and to the following provisions of this section, the medical practitioner primarily responsible for the medical treatment of the adult shall have, during the period specified in the certificate, authority to do what is reasonable in the circumstances, in relation to the medical treatment, to safeguard or promote the physical or mental health of the adult.

Therefore, once the authority to treat is established the medical practitioner may carry out any procedure or treatment designed to promote the wellbeing of the adult (section 47(4)). In situations where the proxy (who believes he or she is acting in accordance with the present and past wishes and feelings of the incapacitated adult) and the doctor disagree then an independent practitioner is nominated to give an opinion as to the medical treatment advocated. If this practitioner agrees with the responsible doctor then the treatment can go ahead (section 50(5)). This situation may cause a conflict between the two decision-making concepts of "substituted-judgement" and "best interests" and ultimately between patient and medical autonomy.

England and Wales

In England and Wales the next of kin has no legal right to consent to or refuse medical treatment (*Re T* [1992] 4 All ER 649), and proxy consents 'are truly valid only when the patient has given express authority to another person to give or withhold consent on his behalf' (Mason & McCall Smith, 1994: 222). Therefore, it is necessary for the incompetent patient to have expressed a desire for another person to make decisions on his or her behalf while still competent to do so. Lord Donaldson MR (*Re T* at 653) drew attention to the right to determine medical treatment in advance. The judgement expressly recognised a patient's right to state in advance

and in writing his or her objection to certain forms of treatment. In order for such a refusal to be binding, the Court of Appeal decided that four criteria had to be fulfilled. The patient:

- Must have capacity to make the decision;
- Must not have been unduly influenced by a third party;
- Must have understood in broad terms the nature and effect of the treatment being refused; and
- The refusal must cover the actual situation in which treatment is needed.

Thorpe J, in a case where an adult refused amputation of a gangrenous leg, reiterated Lord Donaldson's four criteria (*Re T*, 1992) stating that they were 'common ground' (*Re C* [1994] 1 All ER 819). He added '[I]t is also common ground that a refusal can take the form of a declaration of intention never to consent in the future or never to consent in some future circumstances' (*Re C* at 824). In verifying C's capacity to refuse medical treatment now and in the future, The High Court, exercising its inherent jurisdiction, made it clear that it could determine the effect of a purported advance directive as to future medical treatment. These two cases establish, in common law, that an informed refusal of treatment made in advance by an adult who understands the implications of that decision has the same legal power as a contemporaneous refusal.

Investigation of statutory support for advance directives began in 1991 with the publication of the first of a series of discussion papers by the Law Commission in England (Law Comm., 1991). Its remit was to assess the need for reform and to recommend the most practicable way forward. Part VI sets out some options for reform in medical matters and deals *inter alia* with advance directives. It establishes the concept of advance directives as a form of substitutive decision-making, the aim of which is to 'give the person concerned the assurance that his expressed wishes will be followed and his autonomy respected to the highest possible degree' (*ibid.* 138).

At that time there had been no reported decision on the legal standing of advance directives. It was thought that the English courts would follow the position adopted by the New Jersey Supreme Court in the case of *In re Conroy* (1985), which held that, if known, the incompetent patient's earlier wishes would be determinative.

However, it was possible that the English courts would regard these wishes as being merely persuasive rather than imposing any obligation on doctors. With an increased interest in advance directives in the UK, the Law Commission felt 'some clarification of their legal status to be desirable' (1991: 139). Consultation produced over 120 responses by 1993, the majority supporting reform, but without a clear consensus on the form this should take.

In 1993 the Law Commission carried out a further consultation on the role of advance directives as part of an integrated system for making decisions when a patient is incapacitated (Law Com, 1993). By this time the case of Anthony Bland (*op cit.*) had made it clear that the principle of self-determination, which holds that a patient with sound mind could refuse medical treatment, should be applied to patients who are unable to give or refuse consent, if their earlier wishes are known.

One year earlier the British Medical Association (BMA) strongly supported the principle of advance directives as a means for patients to exercise their autonomy in situations where they no longer had the capacity to make decisions. However, the BMA argued that 'mutual respect and common accord is better achieved without legislation' and that advance directives did not have legal force (BMA, 1992: 3-4). In response to this, the Law Commission made several proposals in its Discussion Paper, the main one being that 'legislation should provide for the scope and legal effect of anticipatory decisions' (Law Com, 1993: 31)

The House of Lords Select Committee on Medical Ethics included an examination of advance statements in their final report (House of Lords, 1994). It concluded that legislation for advance statements was unnecessary, fearing it would be impossible to give them greater legal force without depriving patients of the benefit of new treatments and procedures which may become available after the advance statement is signed. At this stage they commended the use of advance statements but were satisfied with them being managed by a Code of Practice.

In 1995 the Law Commission published its Report, *Mental Incapacity* (Law Comm., 1995). The fundamental issue discussed in Part V is the nature and legal effect of views which have been expressed by the person concerning anticipatory decisions on

medical treatment. The Report explains how the recommendations in the 1993 Discussion Paper make satisfactory legal provision to accommodate many of the views that are commonly expressed in advance directives. It recommends specific statutory protection for situations where the patient has decided in advance to refuse some particular form of treatment.

A clear majority of those who responded to the Discussion Paper supported the proposal that legislation should be introduced to govern anticipatory decisions. A majority of respondents was keen to see statutory force given to the common law principle that treating a patient despite a refusal of consent is a civil wrong and may constitute a crime. There was an almost unanimous view that patients should be enabled and encouraged to exercise choice about medical treatment. However, a number of respondents, including the BMA, argued that legislation would be unnecessary and unhelpful, and that the common law could be relied upon to provide adequate guidance. Those with firm religious views opposed the introduction of legislation because they did not wish to see anticipatory decisions by patients becoming binding on doctors in all circumstances.

The Law Commission accepted that there was a need to address the danger that a patient who has made an advance directive could unwittingly be depriving himself or herself of professional medical expertise or of beneficial advances in treatment. However, the Commission did not believe it was open to them 'to omit all reference to the increasingly visible issue of health care advance directives from the scope of the integrated legislative scheme' (Law Comm., 1995: 5.5, p67).

The Lord Chancellor's Department responded to the Law Commission's recommendations by publishing a Consultation Paper entitled *Who Decides?* (LCD, 1997). It contained all the proposals put forward by the Law Commission on advance directives, and in a statement on mental incapacity to the House of Lords, the Lord Chancellor made it clear that

[t]he Government recognises that the Law Commission's proposals on advance statements raise complex issues on which people have strongly held personal, religious and ethical opinions. For this reason, the Consultation Paper specifically seeks views on whether legislation in this area is

appropriate, and if so, what its objective should be. (Hansard, 10 December 1997: column 155)

But in October 1999, Government published its Policy Statement, *Making Decisions* (LCD, 1999), which announced that it had decided that proposals for legislation on advance statements were to be withdrawn. In a speech to the Law Society, Lord Irvine set out the reasons for this decision, stating that the guidance contained in case law, together with the BMA Code of Practice should

provide sufficient flexibility to enable the validity and applicability of advance statements to be determined. The courts have a great advantage over any possible statute ... [and] legislation would risk making advance statements inappropriate and inflexible, with the obvious dangers to the best interests of individuals which that would involve ... [T]o fix into statute now a set of rules, when the case law, influenced by medical advances and the development of precedent, is still evolving, would not be sound (Irvine, Conference on Mental Incapacity, 10 November, 1999: 3).

Following the ruling in *Re C* (1994), the British Medical Journal published several articles in 1995 dealing with the issue of legality. An advisor to the BMA on medical ethics, commented, 'the paucity of legal and ethical guidance on reported oral advance statements makes debate imperative and renders the alternative of having designated surrogate decision makers increasingly attractive' (Sommerville, 1995: 1663). While debate was widened to cover oral statements and proxy decision-making, the point remained, that 'the fundamental legal basis of advance statements is beyond doubt' (*ibid.* 1664). Healthcare managers also began to worry about the lack of clarity in the law and were advised that 'in common law, "advance directives" or "living wills" or advance refusals of treatment are accepted as lawful' (Dimond, 1995: 7).

The British Medical Association has indicated that advance directives could be legally binding on doctors in the future (BMA, 1995a: 5) and its revised Code of Practice, made the position clear:

Common law establishes that an informed refusal of treatment made in advance by an adult who understands the implications of that decision has the same legal power as a contemporaneous refusal (BMA, 1999: par. 4.1, 10-11).

The General Medical Council⁷ more recently has drawn up guidelines for doctors:

Any valid advance refusal of treatment – one made when the patient was competent and on the basis of adequate information about the implications of his/her choice - is legally binding and must be respected where it is clearly applicable to the patient's present circumstances and where there is no reason to believe that the patient had changed his/her mind (GMC, 2002: Para 10).

Recent case law has addressed the issue of decision-making capacity and reinforced the legal standing of anticipatory treatment refusals. *Re AK* ((2000) 58 BMLR 151) concerns a 19-year-old man suffering from motor neurone disease. AK was completely paralysed; tube fed and could only breathe with the aid of a ventilator, his only means of communication was by a small movement of one eyelid. In October 1999 he made an advance statement in the presence of his mother and the nursing team about his further treatment. His instructions were that, if he had a chest infection, he would wish it to be treated, but if he suffered a cardiac arrest; he did not wish to be resuscitated. Eight months later he was informed of the impending loss of his remaining ability to communicate and a few days later he told his carers that he wished his ventilator to be switched off if he could no longer communicate. The health authority applied to the High Court for a declaration that it would be lawful to discontinue artificial ventilation, nutrition and hydration in accordance with AK wishes. The court held that in the case of an adult patient with full capacity his refusal to consent to treatment must in law be observed and in that respect the 'case has reinforced the well-established principle that a competent adult has an unassailable right to refuse all treatment at common law, even if this will lead to death' (Commentary, 2001: 174).

More importantly, for our purposes, is the ruling on the advance directive. Hughes, J. held that '[t]o this extent an advance indication of the wishes of a patient of full capacity and sound mind is effective, but care must be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient' (*Re AK* at 152). This case again reinforces the common law position, that provided the conditions in *Re T* above, are satisfied, then 'there is no doubt that the law will

⁷ The BMA and the GMC guidelines also apply to doctors in Scotland as well as those in England Wales.

recognise the binding effect of a validly made anticipatory refusal' (Commentary, 175).

A further case (*Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449) confirms the right of a competent patient to refuse treatment even if the result is death, but also the facility for conscientious objection by doctors, previously not explicitly recognised in case law. Ms B, a 43-year-old woman, was tetraplegic, relied on respiratory support, and could speak only through a speech valve. There was no prospect of a recovery, although rehabilitation schemes had been offered to improve her quality of life away from the intensive care unit where she had been resident for over a year. Ms B did not feel that she could continue living in this way and had requested the removal of her ventilation (which would ultimately mean her death) since March 2001. Expert opinion agreed that Ms B did have capacity to make such a decision since August 2001, but treating clinicians felt unable to switch off the ventilator, and suggested a one-way weaning process whereby support would gradually be reduced. Ms B rejected this, as well as the rehabilitation scheme, and since no attempts were made to affect her wishes in the following months, she instructed her solicitors to make an application to the High Court seeking a declaration as to her capacity and the legality of her treatment since August 2001.

Dame Butler-Sloss, President of the Family Division, held that Ms B had unquestionably possessed the requisite degree of capacity since August 2001, and that she had been unlawfully subjected to invasive treatment since that time, justifying a small award of damages to recognise trespass. The President pointed out that the 'right of the competent patient to request cessation of treatment must prevail over the natural desire of the medical and nursing profession to try to keep her alive' (Butler-Sloss, P. at 27).

The parameters of capacity were extended in an attempt to resolve the dilemma that the medical staff found themselves in, doctors insisted that the patient could not make an informed decision because her capacity was impaired by the gravity of her situation, when in fact the psychological effects on the doctors themselves was more

than likely to be the problem. One doctor said in evidence that she felt she was being asked to kill Ms B (Stauch, 2002: 233). Ms B's capacity was held to be unaffected:

In the case of Ms B there was no evidence that her capacity since August 2001 had been affected by factors which had been of concern to her doctors, such as the gravity of her condition, her long-term stay in the ICU, psychological regression induced by her physical condition or her lack of experience of a rehabilitation unit. Similarly she had not displayed a degree of anger, ambivalence or inconsistency high enough to strike at the root of her capacity (Butler-Sloss, P. at 202-3).

The President describes the situation where the attitude of 'some hope of life is better than none [as being] a serious danger ... of benevolent paternalism which fails to respect the personal autonomy of the patient' (Commentary, 2002: 2024). She effectively reprimanded the clinicians by awarding damages for trespass and through reinforcing patient autonomy over clinical judgement in her ruling:

When forming a view as to capacity, particularly if the refusal will have grave consequences, the nature of the patient's decision, the values which inform it and the emotional reaction of doctors should not be allowed to detract from the primary question regarding capacity. Place must be allowed for the patient's subjective perspective on the nature of their condition and treatment being offered (Butler-Sloss, P. at 202).

But the problems encountered by doctors treating Ms B were not ignored by the court and rather than ordering her own doctors to cease ventilation, the judgment sanctioned Ms B's transfer to a different hospital where doctors would be prepared to do this.

If there is no disagreement as to the capacity of the patient, but the doctors nevertheless feel unable to comply with the patient's request, their duty is to find other doctors who will do so (Butler-Sloss, P. at 202).

This aspect of the legal judgment 'may be regarded as setting a new precedent for the UK ... [a] course of conduct required by law, a right of conscientious objection' (Stauch, *op cit.*, 233). While the BMA Code of Practice (1995: para 13, 35) specifically outlined the right of doctors, who have a conscientious objection to advance statements, or withdrawal of treatment, to withdraw from treating that particular patient, this is the first time that the courts have addressed the issue in a judgement. The General Medical Council also has drawn up guidelines:

Where a decision to withhold or withdraw life-prolonging treatment has been made by a competent adult patient, or made by the senior clinician responsible for the care of a patient who lacks capacity to decide following discussions with those close to the patient and the health care team, doctors who have a conscientious objection to the decision may withdraw from the care of that patient. In doing so they must ensure, without delay, that arrangements have been made for another suitably qualified colleague to take over their role, so that the patient's care does not suffer. Where they work for a NHS Trust or other employing body, they will also need to consider any contractual implications of withdrawing from the care of the patient, and take legal advice if appropriate (GMC, 2002: para 20).

In England, therefore, the Common Law and the GMC and BMA Codes of Practice throughout the UK provide guidance for the drawing up and execution of advance directives. Recent case law has reinforced the common law position but as yet, this has not been tested to any degree in the courts.

A summary of the legislative conditions in each of the three countries are set out in the table below.

1.1 Summary of Legislative Conditions

	<i>NETHERLANDS</i>	<i>SCOTLAND</i>	<i>ENGLAND & WALES</i>
<i>Legal Tradition</i>	Civil law	Hybrid	Common law
<i>Law in relation to advance directives</i>	Statute	Implied in statute Case law	Case law
<i>Regulation</i>	Legal regulation	Self-regulation (BMA guidelines) Implied legal regulation	Self-regulation (BMA guidelines)
<i>Patient Autonomy</i>	Strong	Implied but weak	Implied but untested
<i>Medical Autonomy</i>	Strong but moderated by legislation	Strong with an implied moderation by statute Also moderated by case law	Strong but moderated by case law
<i>Enforceability of patients' rights</i>	Enforceable by patient and/or proxy	May be enforceable by proxy	Enforceable by patient through the courts

The European Perspective

In April 1995, the Council of Europe was asked by The European Conference on Family Law to examine the desirability of drafting a European instrument to protect adults with incapacity and to guarantee their integrity, rights and independence. A Group of Specialists was set up by the Council of Ministers under the authority of the European Committee on Legal Co-operation (CDJC) with a remit to study and prepare draft principles about the legal protection of incapable adults. The draft recommendations to Member States on principles concerning the legal protection of adults with incapacity were published in February 1999 (Recommendation No R (99) 4 of the Committee of Ministers to Member States). The draft recommendation was sent out to the European Health Committee, the Steering Committee on Social Policy and the Steering Committee for Human Rights to ensure effective protection for incapable adults. Principle 9, using similar language to the Adults with Incapacity (Scotland) Act 2000, addresses respect for the wishes and feelings of the person concerned:

In establishing or implementing a measure of protection for an incapable adult the past and present wishes and feelings of the adult should be ascertained so far as possible, and should be taken into account and given due respect (1999: Principle 9).

There have been a number of developments in European Law. Article 8 of the European Convention of Human Rights is the primary provision as it concerns respect for private and family life. As Nys (1999) states, this is clearly concerned with individual choices as to bodily autonomy. Article 9 (freedom of conviction and religion) is relevant where the refusal of life-sustaining treatment is inspired by religious motives; the most obvious example being the refusal of blood transfusions by Jehovah's Witnesses (*ibid*, 208)⁸.

⁸ Recent voting by church elders in New York may allow members to accept blood transfusions in critical medical circumstances providing they repent afterwards (The Guardian, 15 June, 2000).

The ECHR does not contain any direct reference to an advance refusal of medical treatment, but Nys believes that the Convention on Human Rights and Biomedicine⁹ is of direct relevance. It reads:

The previously expressed wishes relating to a medical intervention by a patient, who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account (1997: Article 9).

As Nys rightly states, "taking into account" is only a weak recognition of the right to refuse medical treatment in advance' (*ibid.* 211). The cautious approach of the Convention reflects the lack of consensus in Europe regarding the validity of an advance refusal of treatment (*ibid.* 212).

Advance Statements and Euthanasia

Dutch Legislation on Euthanasia

Euthanasia – killing another person at his or her request – is prohibited in Dutch law by article 293 of the Criminal Code, but when performed by a doctor under specific conditions, it is taken to be justified (Griffiths *et al*, 1998: 4). The new Dutch law on euthanasia, officially called the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, has fundamentally changed the Dutch Criminal Code, explicitly allowing euthanasia and assisted suicide. The most formal change to the law is that, while it is still a crime to terminate a life on request:

Any person who terminates another person's life at that person's express and earnest request shall be liable to a term of imprisonment not exceeding twelve years or a fifth category fine (Criminal Code, section 293(1)).

The new law allows euthanasia by giving the doctor performing this act a special defence. The section reads as follows:

The act referred to in the first subsection shall not be an offence if it is committed by a physician who fulfils the due care criteria set out in section 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act, and if the physician notifies the municipal pathologist of

⁹ The Convention was signed by 21 Member States of the Council of Europe in Oviedo, Spain on 4 April 1997. It enters into force after ratification by five states, including at least four Member States of the Council of Europe (Article 33(3)). Six Member States have already ratified the Convention; the UK has yet to do so.

this act in accordance with the provisions of section 7, subsection 2 of the Burial and Cremation Act (Criminal Code, section 293(2)).

To avoid prosecution the doctor must convince the regional review committee that he or she has met certain requirements – the ‘due care criteria’. These requirements mean that the physician believed that:

- a. the request by the patient was voluntary and well-considered;
- b. the patient’s suffering was lasting and unbearable;
- c. has informed the patient about the situation he was in and about his prospects; and
- d. the patient believed that there was no other reasonable solution for the situation he was in;
- e. has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care, referred to in parts a-d; and
- f. the physician has terminated a life or assisted in a suicide with due care (Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, section 2(1)).

If the committee¹⁰ is satisfied that all the care criteria have been fulfilled, the Public Prosecution Service will not be involved.

Section 2(2) of the 2001 Act allows the patient to ask for euthanasia in advance in a written request. In the past it was not clear whether a doctor could comply with a request for euthanasia made in advance in writing by a patient who had become incapable of making an informed decision. The new Act changes this situation:

If a patient aged sixteen years or older is no longer capable of expressing his will, but prior to reaching this condition was deemed to have a reasonable understanding of his interests and has made a written statement containing a request for termination of life, the physician may carry out this request. The requirements of due care, referred to in the first paragraph, apply *mutatis mutandis* (Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, section 2(2)).

De Haan (2002) comments that this provision in the Act led to strong criticism by doctors and bewilderment by lawyers and ethicists (*ibid*, 64-65). Some doctors made it clear that they would be unwilling to terminate a patient’s life on the basis of an advance request, because if the ‘due care’ criteria were to be followed, a patient who was unable to give consent would be unlikely to be aware of enduring unbearable

¹⁰ The Committee consists of a lawyer, a physician and an ethicist.

suffering. In spite of the condemnation by the medical and legal establishment the proposal remained unchanged and was accepted by Parliament. While the new law tries to accommodate the patient's right to self determination (*ibid.*, 60), it stops short of giving patients a legally enforceable right to euthanasia by placing doctors under a duty to carry out a request for termination of life. In the broad view, the two Dutch Acts afford protection to both doctors and patients: the Act on Medical Services is weighted more heavily on the rights of the patient, while the Termination of Life on Request and Assisted Suicide (Review Procedures) Act primarily protects doctors from prosecution.

Advance Directives and Euthanasia

Many people have considerable difficulty in accepting advance directives and for them, giving them legislative force is the same as legalising euthanasia. The problem arises because advance directives often tend to be promoted by pro-choice groups. The main advocates of advance directives are euthanasia societies and consequently advance directives are generally associated with end-of-life decisions. One of the largest organisations working towards societal acceptance of voluntary euthanasia and its legislation is the Dutch Association for Voluntary Euthanasia (NVVE). Its objectives include formulation and distribution of "euthanasia statements" (advance directives) where a person can specify the circumstances that would apply in which he or she would wish to request euthanasia (Griffiths *et al*, 1998:53).

Organisations promoting euthanasia and the "right-to-die" also exist in Scotland (EXIT, Friends at the End) and England (Voluntary Euthanasia Society) and, like the NVVE, promote the use of advance directives as a method of making the incapacitated person's wishes known, but not as requests for euthanasia. Other organisations, in the UK (the Terence Higgins Trust, Age Concern) are also proactive in the attempt to gain legislative status for advance directives; they are also organisations that have wider agendas.

Advance directives in Britain have moved through three principal stages of development. Initially advance directive forms were only available from

organisations supporting voluntary euthanasia and were generally viewed as being only applicable to those with a terminal illness. The second stage saw advance directives being used in situations such as persistent vegetative state. The House of Lords in the Bland decision commented that had Anthony Bland ever indicated, before the accident, that he would not, in these circumstances want life-sustaining treatment, such an indication would have settled the matter (*Airedale NHS Trust v. Bland* [1993] 1 All ER 821). The third stage, favoured by the Terence Higgins Trust, provides not only for refusal of treatment but for the option of permitting preservation of life until a nominated person can be called to say goodbye. This type of directive is a move towards a right to choose rather than a right to die (Sommerville, 1996: 34)

While advance directives still concern end-of-life decision-making, there have been attempts to deal with medicalisation and marginalisation of those persons unable to make decisions. Illich (1976) described the way society tries to protect itself from the realities of mental degeneration and death as the ‘medicalization of death’ (*ibid.* 31). The responsibility for the care of the elderly and the dying has increasingly been confined to institutions, hospitals and health professionals, so that society need not confront these facets of human experience. While other aspects of life – birth, ageing, mental and physical illness – have also been medicalised, they have not been marginalised to the extent of death and dying. Advance directives have tried to evolve into a means to ‘empower the individual to make future choices using present mental capacity and knowledge’ (*ibid.*).

Advance directives can only authorise a refusal of treatment, to the extent that if they ‘demand the continuation of futile treatment they have no legal force’ (BMA, 1995: 12). It is for this reason that many people associate them with euthanasia in either passive or active forms. Nevertheless, the BMA believes that an advance directive is a ‘*right to choose* rather than a *right to die*’ (*ibid.* emphasis in original). This is echoed in the Law Commission’s definition:

The purpose of an advance directive is to enable a competent person to give instructions about what he wishes to be done, or who he wishes to make

decisions for him, if he should subsequently lose the capacity to decide for himself. (Law Commission, 1991: para. 6.2)

Summary

This chapter has highlighted the background to and definitions of advance directives that are relevant to this thesis. The differences in the legislative arrangements for medical decision-making have been explained along with the legal framework governing treatment decision-making and advance directives in each of the three countries compared in this thesis: the Netherlands, Scotland, and England and Wales. The aims of the research and the main themes that run through this whole empirical work are also laid out.

Chapter Two reviews the literature concerning autonomy from a medical jurisprudential viewpoint with reference to empirical research relevant to advance directives, autonomy and power. Chapter Three explains the research methodology used in the research. Chapter Four discusses findings from interviews with Dutch lawyers and doctors; Chapter Five examines similar data from Scotland and Chapter Six looks at data from England. Finally Chapter Seven compares the data from the three jurisdictions, answering the research questions and addressing any recommendations for further research. Samples of letters, interview schedules, data analysis themes and various documents are reproduced in the appendices.

Chapter Two Literature Review

Introduction

This chapter looks at autonomy and power from the perspective of the doctor and patient and reviews the literature surrounding advance directives within the areas of bioethics and medical jurisprudence. The bioethical principles of respect for autonomy and justice inform medical decision-making and the ways in which a doctor's professional power can affect decision-making for patients without capacity, and are relevant in addressing how advance directives impact on individual and professional autonomy. A shift in emphasis from "medical ethics" to "bioethics" has transferred ... 'from being internal concerns of the professions to matters of public, political debate' (Ashcroft, 2001: 322) ... and consequently provides a starting point for research on personal autonomy in relation to professional power.

The literature on autonomy and power is reviewed in a systematic manner, beginning with literature on respect for autonomy in general and advance directives and individual and medical autonomy in particular. It continues by analysing critical perspectives on doctor-patient relationships and decision-making and discussing how advance directives affect these areas with reference to conflicts of interest and opinion and conscientious objections to advance directives. Finally, the principle of justice is examined through three areas: advance directives and human rights – rights based justice; advance directives and resources – distributive justice; and advance directives and the legal profession – legal justice.

Respect for Autonomy

According to Beauchamp and Childress (1994), the bioethical principle of autonomy can inform the attitudes of doctors and other healthcare professionals towards treatment decisions and is relevant to investigating how medical decisions are made. It is also relevant to an examination of codes of professional ethics, and the connection between law and public policy (*ibid.* 10-14). While ethical theories, with their abstract principles and rules, cannot contain enough specific information or

guidance to dictate public policy, the bioethical principle of autonomy can provide a moral backdrop for policy and 'an ethical theory can be used not only as a framework to construct policies but also to criticise those already in place' (*ibid.* 14).

It is generally accepted that healthcare ethics consists of four *prima facie* principles based on basic moral commitments (Beauchamp and Childress, 1994). The four principles are:

- Respect for autonomy or personhood;
- Beneficence – engender benefit (if possible);
- Nonmaleficence – avoid harm;
- Justice – consider fairly the interests of all those affected.

The use of the term “*prima facie*” suggests that the principle is binding unless it conflicts with another moral principle – if it does then a choice must be made between them. Rights to bodily autonomy are not absolute since they become curtailed when another party becomes involved (Horan and Mall, 1977: 362).

Beneficence and nonmaleficence both require respect for autonomy: what may be a benefit for one person may constitute harm for another. Gillon (1994) encapsulates these three principles in what may be a new moral obligation – empowerment. He believes 'that empowerment is essentially an action that combines the three moral obligations of beneficence, nonmaleficence and respect for autonomy to help patients in ways that not only respect but also enhance their autonomy' (*ibid.* 185).

Autonomy enables us to make decisions for ourselves, which may be based on deliberation of all the facts, or by ill-considered, emotional or irrational decisions. It includes the right to 'take decisions based on factors other than pure reason, and embraces the right to take a *wrong* decision' (Brazier, 1987: 175). It is part of the growing emphasis on patient autonomy as Tonelli (1996) observes:

... as medical practice has evolved from an ideal of the beneficent physician, practising with little guidance from the patient, toward the acceptance of a nearly absolute right of patients to control the means and manner of their health care, the very boundaries of personal autonomy have been met and forced back (*ibid.* 816).

Autonomy enables us to make decisions based on deliberation, but being autonomous is not the same as being respected as an autonomous agent. Respect for autonomy involves acknowledging a person's right to make choices, to hold views, to have values and beliefs and to take actions based on these values and beliefs (Beauchamp and Childress, *op cit.*, 125). It is 'the moral obligation to respect the autonomy of others in so far as such respect is compatible with equal respect for the autonomy of all potentially affected' (Gillon, 1994: 184). In Kantian terms it is acting 'so that you treat humanity ... always as an end and never as a means only' (Kant in Singer, 1994: 279).

Autonomy requires the capacity to think and make decisions consistent with one's own values and the ability to act freely without undue influence from others. Patients exercise their autonomy in healthcare settings through the use of informed consent to medical procedures. Consent may be given through non-refusal of various procedures, explicitly through a signature on a form consenting to surgery or it may be implied for example, when a patient allows an injection to be given, or blood to be taken. Three elements are required, however, for informed consent to be valid: first the patient must be competent to give consent; in general there is a presumption of competence in adults unless rebutted by a medical practitioner who has reason to believe a person no longer has the capacity to give consent. Second, the person must be able to understand and appraise the information provided. This may difficult to determine, but a medical practitioner has an obligation to help the patient's understanding as much as possible. Third, the patient must give his or her consent freely, without coercion or manipulation and without being subject to undue influence (Young, 1998: 442-43). Only when these three elements are satisfied can the patient truly give or refuse informed consent.

Autonomy may be thwarted by external forces or by loss of capacity (agency) and in such circumstances consent will be invalid (Clarke, 1999: 459). It is this loss of agency and the consequential loss of autonomy that advance directives attempt to address through respecting the person's earlier autonomy in instructing others to make decisions on his or her behalf.

As mentioned above, respect for autonomy (as well as beneficence, nonmaleficence and justice) can be overridden by competing moral considerations. Autonomy will only be respected where it does not harm others, endanger public health or unfairly demand scarce resources, to mention but a few overriding factors. It is sometimes agreed that 'the principle of respect for autonomy should be viewed as establishing a stalwart right of authority to control one's personal destiny, but not as the only source of moral obligations and rights' (Beauchamp and Childress, *op cit.* 126).

The basic sense of autonomy is the ability for individuals to act intentionally, to carry out actions and to formulate reasons for these actions. It requires intellectual capacity and freedom of choice to make decisions and to act upon them, in short 'to be an autonomous person is to be an intentional agent' (Doyal, 1990: 4). This basic autonomy, or 'first order' autonomy as Doyal calls it, is a very basic form of autonomy. In healthcare terms, it is the autonomy shown by the compliant patient who relinquishes his or her choices to the clinician, who signs the operation consent form without any clear understanding of what it entails. This type of autonomy is compatible with medical paternalism as long as the doctor has not manipulated or coerced the patient against his or her wishes (*ibid* 5).

'Second order' autonomy requires individuals to have capacity to understand and the opportunities to exercise a critical faculty when it comes to making decisions. In healthcare, patients exercising this type of autonomy do not merely agree or disagree with treatment options put to them, they must also understand, to some extent, their illness, the different treatments available and advantages and disadvantages of each option. These strongly autonomous patients 'may well insist on better information, better communication, better clinicians, and even different approaches to treatment itself' (*ibid* 6). In this way the doctors' treatment decisions may have to be made differently because of greater patient autonomy: 'the increasing emphasis on consumerism and "patients' rights" sometimes results in a demand for treatments [or non-treatments] which the doctor may consider inappropriate' (Horner, 2000: 414). The following section reviews a selection of recent literature which discusses the differing autonomy that is afforded to professionals and individuals, which is referred to as 'professional autonomy' and 'individual autonomy'.

Professional Autonomy

A professional, whether medical practitioner or lawyer, has a relative monopoly over his or her work, and enjoys a great degree autonomy. Professional autonomy derives not only from the nature of the work performed, but also from the relationship of the profession to institutions that are external to it, for example the government and society at large. It may only be preserved so long as the profession meets the responsibilities expected of it by these institutions (Swick, *op cit*, 612).

By conforming to its expectations the state ensures doctors' and lawyers' professional autonomy: for example, it is only doctors who may issue death certificates and only lawyers who may be paid for transferring interests in property. The state also provides the opportunity for those professions to practise within a rather restrictive social order and the professions in turn, through self-governance, reinforce the existing social order (Dingwall & Lewis, 1983). Professionals continue to enjoy positions of power and control over their clients, but a corollary of this power may be disempowerment of those requiring services.

In the case of healthcare, the government hands over autonomy to physicians on the understanding that, as professionals, they will put the welfare of both the patient and society above their own interests, and that they will govern themselves by a code of ethics. The central element of professional autonomy for medical practitioners is

the assurance that individual physicians have the freedom to exercise their professional judgement in the care and treatment of their patients ... [it is] ... an essential component of high quality medical care and therefore a benefit due to the patient that must be preserved (World Medical Association, 1987: Declarations 1 & 2).

Professional autonomy represents the freedom of doctors to secure treatments, to prescribe medicines and to provide healthcare according to their own judgement, without interference from the state or from private interests. In this view, it is beneficial for patients because it sets no limits to medical intervention other than those imposed by the limits of medicine itself and by its ethical codes (Dupuis, 2000: 294). In the UK, professional autonomy may be described as the successful outcome

of a struggle of power between the medical profession and society. The moral justification is its protection of patients ‘within a state run health care system, offering potentially unlimited resources to the care of the individual patient, professional autonomy offers that patient the highest available standard of care’ (Horner, 2000: 416). This author raises the point that professional autonomy means that doctors have the freedom to control (through their professional organisations) recruitment, training and practices and control over the conduct of individual members, who each have clinical autonomy. The point being that professional autonomy can be considered as the collective right of a profession, and the individual right of each doctor within that profession (Dupuis, *op cit.* 495).

In the Netherlands, the “guild-free-choice” healthcare system ensures professional autonomy among clinicians that is only limited by the medical profession itself. The doctor can almost freely select medical resources and interventions; these are only restricted by treatment decisions made within a framework of legislation and professional guidelines. The medical profession is assumed to adopt a high standard of self-regulation and the ‘guild-free-system is based on the expectation that doctors will serve society and not exploit their professional autonomy for their own personal interests’ (Polder and Jochemsen, 2000: 482-3).

A comparison of the healthcare systems in the Netherlands and the UK in relation to professional autonomy is depicted in the table below.

2.3 Professional autonomy in different healthcare systems

	<i>NETHERLANDS</i>	<i>UNITED KINGDOM</i>
<i>Type of healthcare system</i>	Guild-free-choice	Centrally planned
<i>Professional autonomy</i>	Nearly unlimited	Limited to a budgeted volume of care
<i>Controlling agency</i>	Medical profession Specific legislation	Government and professional body
<i>Main governance problem</i>	Increasing health expenditure	Quality of care Distributive justice

(Adapted from Polder and Jochemsen, 2000)

Professionals' autonomy in their work requires some control over their clients, manifested by determining the work to be done and how it should be carried out (Freidson, 1986: 216). Professionals claim, and are often accorded, complete autonomy by their clients because they are presumed to be the only judges of how good their work is and because no layman or outsider can make this judgement. Cain argues that the concept of a "profession" obscures more than it reveals about the work professionals do. For example, in the case of lawyers, it is difficult to tell whether a lawyer has done a good job (1983: 106). When a professional's work is difficult to evaluate this can represent a degree of power over a client, characterised by clients' relative impotence, their control by professionals, and the difficulties they have over understanding the issues in legal terms (*ibid*, 129). Hoogland and Jochemsen see this being the paradox of autonomy where two poles exist: autonomy is essential for members of a profession to fulfil their roles as professionals, but this autonomy makes it very difficult to make sure that they are fulfilling their roles adequately (2000: 459). An unbreakable circle is created: the professionals' specialist knowledge creates the professional power, that power is used exclusively in the client's best interests, but these best interests can only be judged by the professionals themselves, because they have the specialist knowledge, and so it goes on (Mungham and Thomas, 1983: 148).

Individual Autonomy

Individual autonomy refers to agency, in the form of an awareness of oneself with desires and goals, being able to act upon them and rationality to critically reflect on them. It also refers to self-governance and the independence to act without outside controls, free from coercion and manipulation with the right to make decisions against other individuals or the state (Verkerk, 1999: 360). Respecting a person's autonomy recognises the attributes that give humans their moral uniqueness. Humans, unlike animals, 'formulate aims and beliefs, reason about them, make choices on their basis, and attempt to plan for the future' (O'Brien and Chantler, 2003: 36).

There are several reasons why it is a good idea to support individual autonomy in making choices. Economic efficiency proposes that people are better off if they are

allowed to make their own choices about goods and services and, by offering better value through lower prices and better quality, consumers have the potential of making gains. Rice claims that this belief is exemplified by the “theory of revealed preference” - ‘allowing people to make their own economic choices will, in and of itself, make them best off’ (Rice, 2001: 240). Individual autonomy is also substantiated through the psychological satisfaction people get out of goods and services they choose themselves. Because consumer decisions, and in particular consumer decisions that involve healthcare needs, are so individualistic and personal, it is more likely that people will be better qualified to make their own choices. This in turn may assist in creating a positive therapeutic environment (*ibid* 241). Finally, in the spirit of equity and fairness, individual autonomy could dictate that it is unfair to tax one individual’s resources to spend on others. However, drawing on Rawls’ notion of fairness in determining how resources are distributed, Rice concludes that the policy implication is ‘to ensure that individuals who are at a disadvantage have an equal probability of attaining good health, it is necessary to redistribute resources from those who have been more fortunate’ (*ibid* 242-3).

Doyal and Gough (1991) describe a minimal sense of autonomy in which the individual has ‘the ability to make informed choices about what should be done and how to go about doing it’ (*ibid.* 53). Our reasons for making these choices, connect us with our actions, and our capacity to make mistakes ‘performs the same role as regards the successes and failures of our actions’ (*ibid.*) In expressing autonomy, the individual formulates consistent aims and strategies that are believed to be in his or her best interests and attempts to put them into practice. The degree by which this individual autonomy can be increased is affected by three key variables. First, the degree of understanding a person has about his or herself and about his or her culture, which depends on the cognitive skills learned from others. Second, the individual’s cognitive and emotional capacity is an important component, illustrated by the reduction in autonomous decision-making allowed to the mentally ill. Third, the range of opportunities for new and significant actions open to the individual means that improvements in autonomy can be linked to increased and significant choices; what was minimal autonomy now becomes critical autonomy (*ibid.* 59-67).

In the field of healthcare, critical autonomy becomes the reasoning behind medical confidentiality, and the obligation to obtain informed consent from patients and to respect their decisions. Respect for autonomy and respect for self-determination in persons using healthcare services has been expressed in several medical laws in the Netherlands (Verkerk, *op cit.* 361). In the law on Contracts for Medical Treatment (WGBO) 1995, patients' rights are defined through the right of informed consent and the right to refuse medical treatment. The law on Special Admission to Psychiatric Hospitals 1994 (Wet Bopz) defines the legal position of psychiatric patients who may be compulsorily detained in hospital. Coercive admission to hospital and coercive treatment are no longer justified in the patient's best interests and are overruled by the right of self-determination in all but extreme cases.

When a patient exercises his or her autonomy in a healthcare situation, he or she decides which treatment option to consent to in dealing with the particular health problem, taking into consideration his or her goals, values and wishes. Normally this causes few problems since the patient and the doctor are in agreement, but recognition and respect for the patient's autonomy will be more seriously tested when the patient's choice conflicts with that of the clinician. Where the course of action is not in the patient's best interests and is even detrimental to his or her well-being, it may appear to the doctor that these choices are unbalanced and there will be a temptation to overrule the patient by questioning his or her mental capacity. However, as is quite correctly stated 'disagreement as such cannot be taken to signify that the patient is incompetent' (Young, 1998: 442).

Advance Directives and Autonomy

Discussion of advance directives or "living wills" focuses on the moral principle of respect for autonomy. Vernon (1996) admits that medical treatment often occurs without moral difficulty and 'doctors usually take clinical decision making for granted' (*ibid.* 604). He sees anticipatory decisions as providing a mechanism for preserving patients' autonomy when they are incapable of making their own decisions. He believes that the 'living will, when properly drawn up and executed, is perhaps the best device available to ensure respect for prior autonomy' (*ibid.* 605).

Advance directives have raised serious issues of autonomy and justice in the medical, nursing and medico-legal literature in the last decade. The idea of using anticipatory decision-making as a means of extending personal autonomy into the future has been welcomed by the majority of healthcare professionals but a significant minority has serious doubts as to the efficacy of the advance directive. Further disagreement is apparent in the debate on the legal status of advance directives.

Childress (1982), in discussing decision-making and paternalism, comments that the significance of statements made in advance means that unless the person has revoked them, or was incompetent when they made them, they determine what ought to be done. Use of advance directives as a decision-making tool may be a way to determine what ought to be done.

In an article analysing three inter-related concepts relevant to advance directives – rights, values, and personhood – Rashid (2000) notes that Codes of Conduct, information guides, etc. uses “rights” language (BMA, 1995a; RCN, 1994; Patients Association, 1995). She believes

... such language implies there are certain morally justified claims or entitlements that are beyond question and universally applicable ... [but] ... there can be potential conflicts between the “rights” of different individuals ... (Rashid, 2000: 38).

In assessing advance decision-making, Rashid refers to the Kantian principle of the autonomy of the individual, which holds that personal autonomy is an absolute value, whatever the circumstances. The BMA in its code of practice on advance statements states:

Personal autonomy although important, cannot always be an *overriding* ethical principle. In most situations the individual’s right to refuse treatment *outweighs* any *competing interests*, including the wishes of other people. In exceptional circumstances, the individual’s choice has unacceptable consequences; such as potentially serious harm for others, which is sufficient, to *outweigh* the patient’s right of refusal. Others may be harmed if refusal of basic care leads, for example, to the spread of infection (1995a: 15, emphasis added).

Contrary to Kant's view, the advance statement cannot be seen then as having an absolute value or being an overriding ethical principle. Rashid claims that while the opening reference to personal autonomy in the BMA's Code of Practice implies a Kantian commitment to the autonomous individual, the remainder of the passage uses utilitarian language in the tradition of Bentham and Mill, in referring to the balancing of interests.

There is an argument that autonomy can be damaging to the doctor-patient relationship. Kessel and Meran (1998) see a 'legitimate concern that the corollary of individualism and technological advancement is diminishing communication with doctors, which may result in patients being literally abandoned to their own autonomy' (*ibid.* 1265). The suggestion that advance directives refer only to a refusal of treatment and may reflect a lack of faith in doctors may support such concerns. This is echoed in the debate on euthanasia, where 'this "right to die" is asserted within the bounds of a patient's autonomy' (Sobczak, 1997: 878). This does nothing to diminish fears that advance directives are but a step away from legalising euthanasia.

Fears that a person's advance directive will not be taken seriously and subsequently not followed are likely to be damaging to the doctor-patient relationship. In a survey of American nurses, one-quarter of the nurses claimed that they had seen a doctor or other healthcare provider deliberately disregard an advance directive; among those working in critical care, the proportion was more than half (Wolfe, 1998: 51). Many different reasons for ignoring directives were suggested, including the doctor found the patient's instructions ambiguous; the patient could not have anticipated specific treatment choices; the doctor felt compelled to respect a family's request to override a patient's wishes; and the doctor did not agree with the directive on medical grounds. In situations such as these, the nurse is in a 'no win situation' – he or she must follow the doctor's instructions even if this means overriding or ignoring a patient's previously expressed wishes (*ibid.*).

Objections to advance directives on the grounds that they do not necessarily increase patient autonomy often raise the issue of informed decision-making. Ryan (1996: 96)

argues that autonomy cannot be exercised without full possession of all the information that might influence a decision; consent being valid only if the patient has been informed of all the risks and consequences of the treatment. A person who makes provisions in a living will may not have access to all the information that could affect his or her decision and Ryan maintains that, in this case, the person is making a decision in the present about a hypothetical situation in the future. While he concedes that the individual is in the best position to know how he or she would act in that situation,

... most people have no experience of their reactions to a life-threatening illness, they can only guess at their reaction and they frequently guess wrong ... [and] ... people do not believe in, or even know of the possibility of, an inaccurate guess ... the lack of vital information prohibits a fully informed and autonomous choice (*ibid.* 97).

When a person executes an advance directive it may be some time until the directive comes into force, in some cases several years. The gap between writing the directive and the person's incapacity is an area of concern for opponents of advance directives, who claim that a person's choices may change over time. Emanuel *et al* (1994) investigated this problem in a prospective cohort study of 495 outpatients and 102 members of the public, in which the research subjects completed an advance directive that included four illness scenarios and 11 treatment choices. Follow ups were undertaken after 12 and 24 months. To realise personal autonomy, the choices expressed at one point in time must correspond reasonably well with those expressed subsequently. The study found that

patients and members of the public can make scenario and treatment-specific advance choices that are reasonably stable; that their choices become more stable with repeat consideration, especially if they have discussions with their physicians; and that illness ... had little effect on the stability of choices. The findings also suggest that stability may be improved by periodic review of decisions and discussion with physicians (*ibid.*, 214).

Although discussions between doctor and patients appear to be important in many aspects surrounding advance directives they are not without their own difficulties. From the physician's perspective a number of barriers including lack of time, lack of administrative support, perceived legal uncertainties and lack of proper knowledge or

expertise are reported to inhibit discussions of advance directives (Markson *et al*, 1994: 2324). Lack of knowledge of advance directives is frequently an obstacle for the patient and the doctor, and general practitioners are not particularly effective in promoting discussions of patient preferences for end-of-life care (Gamble *et al*, 1991: 279).

A reticence to encourage patients to express their treatment preferences in an advance directive is found in the policies of the NHS. In guidance to clinical staff, the Newcastle Upon Tyne NHS Trust Clinical Ethics Advisory Group (CEAG) advised that, while patients should be made generally aware of living wills, this would not be routinely raised with all patients. The reasons for this are that patients might feel that undue pressure is being brought to bear on them, 'breaching the principle of nonmaleficence and potentially undermining the patient's trust in their health carers in hospital' (CEAG, 2001: 3).

From the patient's perspective, one researcher found that many elderly patients do not discuss their advance directive with their doctor because they perceive it to be "private" in the way that a testamentary will may be (Wolfe, 1998: 52).

Advance Directives and the Medical Profession

Medical practitioners have traditionally been given considerable liberty in their professional work, and often appeal to the right to "clinical freedom" when outside influences threaten to control their practice (Warren, 1979). Berger (2002) comments that a doctor's knowledge, and thus his or her power over a patient is a critical variable in the development of arrogance among doctors, deluding 'some physicians into imagining that they are all-powerful' (*ibid* 145). Treatment decision-making for patients unable to decide for themselves can allow doctors ultimate power to decide on behalf of another. This power may be conceptualised as a continuum along which the wishes of the patient compete with doctors' opinions: 'at one end the physician honours the wishes of the patient; at the other, he or she does not' (Johnson, 1996: 569).

Advance directives may be viewed as a method of eroding the doctor's power and some worry that they may compromise the autonomy of the professional (Higgs, 1987: 1221). Doctors in the UK are obliged to follow a competent person's wishes regarding treatment, while in the case of an incompetent patient the doctors must act in the patient's best interests. Following a patient's treatment requests in an advance directive, for example, a refusal of pain relief, which would be not be likely to be in his or her best interests would probably be ignored. The ultimate power therefore being in the hands of the clinician (BMA, 1995a: 35).

In 1999, the NHS Executive issued guidelines on withholding consent to treatment and the GMC (1999) issued guidance on the current legal position on advance directives. In order to discover what provisions had been made to recognise advance directives through actual or intended policies, Diggory and Judd (2000) conducted research on 463 NHS Trusts. Half (124) of the Trusts that responded had already developed or intended to develop policies on advance directives but 28% (70) did not intend to develop policies. In 94% of the trusts surveyed, ward staff were given no guidance on advance directives. The researchers recommend that 'national guidelines should be developed to support a consistent approach to tertiary care across the NHS for patients with advance directives' (Diggory and Judd, 2000: 25). According to NHS Trusts, by initiating policies and consequently restricting a doctor's freedom to make decisions in relation to advance directives are circumventing the boundaries of clinical freedom which a doctor enjoys 'by authority in various guises' (Warren, *op cit.*).

A major objection to making advance directives binding on doctors is that the autonomous demands of the patient may clash with the "rights" of doctors to follow their conscience (Guild of Catholic Doctors, 1999). In its booklet on the use of advance statements, the Guild addresses the questions of whether advance directives are legally binding. The advice given is misleading in some respects, for example stating that the BMA considers advance statements not binding on health professionals, but deserve thorough consideration. This is inaccurate as the BMA clearly states in its Code of Practice that where they are valid and applicable,

advance statements must be followed (1995a: para. 14.2). This booklet illustrates the diversity of opinion from both a medical and religious perspective.

Some doctors regard advance directives as a 'benchmark in the decline of respect for clinical judgement, predicting that doctors will become mere technicians subject to inappropriate and perhaps outdated instructions from now incapacitated individuals' (Sommerville, 1996b: 9). They are concerned that this will clash with the obligation to act in the patient's best interests and fear that they are part of a trend indicating a lack of trust in the doctor-patient relationship, which will lead to increasing confrontation and litigation (*ibid*).

Samuels (1996) comments that the advance directive may represent a lack of trust in doctors to do the right thing when the patient becomes incapable and states that by restricting the clinician's decision-making his or her autonomy will be impeded or inhibited (*ibid.*, 3). This concern had been previously addressed by the House of Lords Select Committee which advised against making advance directives legally binding on the grounds that, they 'would gravely undermine the professional expertise and judgement of doctors. It would make doctors nothing more than slaves of society' (1994: para 196).

In a letter to the British Medical Journal, the Bromley division of the BMA expressed its concern at the Association's stance over advance directives stating that 'advance directives should have been opposed as being incompatible with good medical practice and ethics rather than accepted as a *fait accompli*' (Jessiman, 1996: 851). Ending on an ominous note, the letter warns anyone contemplating using this type of anticipatory decision-making that 'medical staff tend to avoid those who spurn their best endeavours, and patients' care will suffer in consequence' (*ibid*). An equally forthright reply followed disagreeing with the previously expressed views and supporting advance directives as reflecting both good medical practice and a legal obligation to respect a patient's wishes. The author strongly expresses the view that 'carrying out treatments contrary to the patient's stated wishes and getting away with it because the patient is not mentally or physically competent to resist, is something that no doctor or the BMA could sanction' (Finfer, 1996: 1539).

Perhaps doctors' problems with advance directives stem from lack of information and knowledge. General Practitioners in London and Winchester were asked questions about the current legal status of living wills (Bowker *et al*, 1998). The doctors were asked to indicate whether they were aware that some forms of advance directive could carry legal force. The results of the survey show that only half (107) of the GPs surveyed were aware that living wills currently carry some legal force under English law. Most of them were ignorant of important aspects of the law. The researchers comment that they believe that the lack of specific legislation in this area has contributed to doctors' confusion about the legality of living wills. A postal survey investigating doctors' knowledge of advance directives was conducted in Dorset and questionnaires were sent to 80 hospital doctors and 80 GPs in over four NHS trusts. Of the 89 doctors¹¹ who replied, 17 hospital doctors and 21 GPs had not heard of the BMA's guidance on advance statements. The researchers comment that there is a clear message that the medical profession needs to address how best to inform and train doctors about advance directives (Zaman and Battock, 1998: 147).

A similar study was conducted in South Australia in 1991, where living wills have been legally binding since 1983. A postal questionnaire was sent to a random sample of 158 General Practitioners, 117 (74%) of whom replied. Sixty-three per cent (74) of the respondents were aware of the provision for living wills with 23 of them having forms in their office, 41 had discussed them with their patients. Of the 21 doctors whose patients had made a living will, 12 had considered it helpful in decision-making and five were undecided, while 4 thought that it had not been useful. The main concern of the GPs was that they had difficulty in raising the subject of living wills with their patients because of the possibilities of an adverse effect on the doctor-patient relationship and generating disagreements between doctors and families over treatment decisions. The authors believed that lack of knowledge of the Natural Death Act 1983 in South Australia was an impediment to effective use of living wills and that a "raising awareness programme" was necessary for GPs and the public. They conclude that 'any form of living will, advance

¹¹ Forty-two (53%) hospital doctors and 47 (59%) GPs.



directive is intended to clarify what the patient wants and so should be an ally of good medical practice, not a troublesome intruder' (Ashby *et al*, 1995: 230).

If advance directives are to be useful as a means of maintaining an incapacitated patient's autonomy, there needs to be an awareness of their existence and their function not only by doctors, but also by the public. Little empirical research has been carried out on advance directives in the UK but a comprehensive piece of research was carried out by the Office for National Statistics on behalf of the Department of Health in 1996 (ONS, 1996) showed a lack of knowledge on advance directives within the general community. Questions concerning advance directives were asked in order to measure how many people knew what an advance statement/advance directive/living will could authorise. Only 7.1% (131) of respondents replied to this question, and just over half (75) of whom were aware that advance statements concerned medical treatment but could not authorise euthanasia. The remainder of the respondents were either unsure or had some other understanding of advance statements.

Contrary to the belief that advance directives erode doctors' power, Tonelli (1996) believes that the right of patients to control their healthcare and make their own treatment decisions through the use of advance directives places the doctor in a position of ultimate power. The need to encompass a vast array of medical conditions and illnesses in an attempt to cover all eventualities produces an inherent vagueness in living wills and leaves them open to interpretation by the clinician,. Additionally, the point at when an advance directive comes into effect is also left up to the doctor in charge of the patient's care to decide and 'by ceding to physicians the power of determining if and when advance directives are going to be applied, patient autonomy is not protected against the paternalistic practitioner' (*ibid* 818).

Doctor-Patient Relationships and Decision-making

At the core of medical practice is a need to create and nurture a trusting dyadic relationship between physician and patient. The literature overwhelmingly cites communication as being the bedrock of the relationship between doctor and patient -

‘the purpose of communication is not to convince the patient to do what the physician desires but to understand the patient’s concerns and to make decisions acceptable to both the patient and the physician’ (Herndon and Pollack, 2002: 309). This section examines the literature on different models of medical decision-making beginning with the decision-making process. This is followed by a discussion of the most commonly used models of decision-making for incapacitated persons: “best interests” and “substituted judgement” models. It concludes with a review of alternatives to these models before moving on to a discussion of how advance directives can affect decision-making.

As doctors are professionals, in order to adhere to the core elements of professionalism (altruism, accountability, excellence, duty, integrity, respect for others, etc.) there needs to be effective communication between doctor and patient and between doctors and their colleagues. However, effective communication cannot exist in the absence of a solid, trusting physician-patient relationship; the two are inextricably linked (*ibid*). Emanuel and Dubler (1995) suggested “Six Cs” in facilitating effective doctor-patient communication. They are:

- *Choice* – treatment options
- *Competence* – expected of doctors by patients
- *Communication* – doctors must listen, understand the patient’s pain or problem, and communicate
- *Compassion* – patients want technical proficiency but also empathy
- *Continuity* – the patient-physician relationship should endure over time
- *(No) Conflict of interest* – the doctor’s primary concern must be for his or her patient – the patient’s wellbeing must take precedence over the doctor’s own personal interest

Medical decision-making both for patients with capacity and those unable to make their own decisions requires a balanced consideration of medical, ethical, psychosocial, and societal aspects (van der Heide *et al*, 2003: 1). Patients, relatives and healthcare professionals are all involved in treatment decision-making to some degree and the preceding aspects and the legal arrangements in different countries can modify the decision-making practices and attitudes of the parties involved.

In their discussion on the criteria for medical decision-making, Hertogh *et al* (1996) argue that every medical decision is based on two categories of norms: professional medical norms and societal norms. Professional medical norms or professional medical standards are an expression of professional autonomy. Societal norms are reflected in the patient's preferences and the treatments that he or she has given consent to. However, respect for medical or patient autonomy is not absolute but is a reciprocal limiting principle, under which the doctor has a duty,

to perform only those actions for which he/she has been given permission ... and it restricts the patient in that he/she can only ask the physician to do what the physician considers to be in keeping with the standards of proper care (*ibid*, 14-15).

The doctor's duty of care is protected, in the case of the Netherlands, by the Dutch Act on Medical Treatment Contract in which the legislature has determined that,

The care provider must in the course of his duties have regard for the standard of care required of a competent care provider and must act in accordance with the responsibilities ensuing from the standard of professional care required of care providers (Article 453).

By ensuring that the doctor must act according to professional standards, the intention is that the Act offers protection against requests to perform medical procedures that are in conflict with those standards (Hertogh, *op cit.*, 15). Interestingly, if the patient does not have an advance directive and has to rely on a representative to make his or her treatment decisions, the Act does qualify how those decisions should be made or whether the decisions should be in the patient's best interests.

The BMA has produced guidelines on decision-making for incapacitated patients. In addition to recommending clinicians to follow any local or national guidelines for doctors in the UK, the BMA (1999) advises doctors to: involve the multi-disciplinary team (section 17.8); take account of the patient's previous views (section 18.2); consult with family and close friends of the patient (section 18.3); and secure good communication with all parties involved (section 18.4).

Substituted Judgement

The courts in the United States have stated that substituted judgement is the 'means by which incompetents can exercise their right to refuse or terminate treatment' (Martyn, 1994: 196). In Saikewicz (1977) the court applied a 5-pronged test to determine the values and desires of the individual. The test required analysis of:

- The expressed patient preferences;
- The patient's religious convictions;
- The impact on the patient's family;
- The patient's prognosis with or without treatment; and
- The probability of adverse side effects.

The first two factors are subjective and require a personal knowledge of the patient; the third factor takes the family's views into account, something that is not included in other definitions of substituted judgement. The last two factors rely on more objective information which can be obtained from the clinician in charge of the patient's care. The decision obtained from substituted judgement 'must be based either on expressed preferences or inferences deduced from conscious volitional actions' (Martyn, 1994: 197).

The term "substituted judgement" refers to a patient-centred criterion where the wishes of the patient prevail. It is a weak autonomy-based standard (Beauchamp and Childress, op cit. 171) where the surrogate decision-maker is required to 'don the mental mantle of the incompetent' (Saikewicz, 1977). The judgement in question is the patient's judgement and the decision-maker or proxy is a substitute for the patient who makes the decisions on the patient's behalf (Deverette, 1995: 110). As a substitute model of decision-making, a treatment plan previously chosen by the patient can be authorised or, if no plan was made, the situation can be assessed and the decision that the proxy believes the patient would have made can be carried out.

Thirty-three physicians, bioethicists, and medical economists from ten countries met at Lawrence University, Appleton, Wisconsin in 1989, to create The Appleton Consensus: International Guidelines for Decisions to Forego Medical Treatment. The guidelines deal with four specific decision-making circumstances:

- Five guidelines were created for decisions involving competent patients or patients who have executed an advance directive before becoming incompetent;
- Thirteen guidelines were created for decisions involving patients who were once competent, but are now incompetent, who have not executed an advance directive;
- Seven guidelines were created for decisions involving patients who never have been competent, for whom “no substituted judgement” can be rendered; and
- Eleven guidelines were created for resource-led decisions (Stanley, 1989).

The major criticism of the substituted judgement standard is the failure of the surrogate decision-maker to make correct decisions for the incapacitated person and the poor success rate in making choices is a major reason for non-involvement of proxies. In the absence of specific instructions, the decision is often an optimistic guess (Emanuel and Emanuel, 1992: 2068). Doctors have difficulty taking the surrogates’ decisions seriously when only about 50% of the decisions are in agreement with decisions the patients would have made (Dubler, 1995: 298-301).

In a review of empirical studies on proxy decision-making, Emanuel and Emanuel (1994) found three major flaws in this method of decision-making. First, they found that discussions of treatment issues between patients and their proxies were uncommon, particularly in the area of resuscitation and treatment withdrawal. Second, they found that family members are unreliable in assessing a patient’s quality of life, usually erring by underestimating of the patient’s functional status. Emanuel and Emanuel (*ibid*: 2069) note that ‘if a proxy’s assessment of the patient’s quality of life is indispensable to making an accurate decision about terminating care, then this research casts doubt on the capacity of proxies to make valid substituted judgements’ (*ibid*). Third, proxies were found to be unable to accurately predict patients’ preferences for life-sustaining treatments and were not much better at predicting patients’ other preferences during incompetence (*ibid*). Similar problems arose in a study of surrogate decision-making preferences for nursing home patients in the absence of advance directives. The researchers were concerned to discover that ‘decisions were infrequently based on views the resident held and expressed while competent. ... [and] ... nearly 75% of surrogates indicated that their decisions were not at all based on residents’ statements or comments’ (Cogen *et al*, 1992: 1887-88).

Similar problems afflict doctors' decision-making in the same situations. In a study of surrogate decision-makers' views (family members and primary care providers) 'neither physicians nor designated family members met criteria for accuracy in their predictions of patients' wishes' (Seckler *et al*, 1991: 95). One of the conclusions of this study is that doctors might have difficulty leaving their personal quality of life assessments aside when asked to make substituted judgement decisions (*ibid*). Other studies have also found that doctors substitute their own preferences for those of their patients (Schneiderman *et al* 1993: 28; Orentlicher, 1992: 2102). Extending their observations to a larger population, the researchers' findings remained the same with doctors predicting that patients' treatment choices were closer to their own choices than the ones the patients would have made. Since doctors ultimately exercise control, Schneiderman, (1997) concludes that this raises serious concerns about physicians acting in a substituted judgement capacity' (*ibid* 131).

The substituted judgement model is only really useful if the decision-maker knows what the patient would have wanted. There are three ways that someone could know this,

- The patient could have explicitly told someone, orally or in a written directive, what he or she wants done;
- The patient could have implicitly made clear what he or she wants – previous conversations, offhand comments, etc;
- The patient could have revealed enough about his or her thinking and values so the person knows even though it was never actually discussed (Deverette, *op cit.*, 111).

The third option is a weak and unsatisfactory basis for substituted judgement decisions and would only really apply if the relationship between patient and other person was really close, e.g. couples who enjoyed a happy and communicative relationship. Finally, in assessing whether substituted judgement could be an alternative to using an advance directive to indicate patient preferences, Emanuel *et al*, found that 'in the absence of direct discussion with patients, substituted decision making is not likely to correspond with their preferences' (1991: 895).

Best Interests

When the patient's wishes are not known or cannot be discerned, the clinical team has to rely on the "best interests" test to determine treatment decisions. The interests are those of the patient and what will be of benefit to him or her, all things considered, i.e. what is good for that patient at that particular time (Deverette, *op cit.*, 113). The best interests standard should guide treatment choices by focusing on the person and the alternatives available and identifying the most acceptable of available options (Kopelman, 1997: 277-79). Used as a model for medical decision-makers, it is often used as a "standard of reasonableness" where the best treatment may be justifiable for various moral and resource-led reasons (*ibid*, 281).

The Appleton Consensus Guidelines for medical treatment decision-making recommend that decisions should be made using the best interests standard when there is no clear indication which plan of care the patient would have preferred. They advise discussion with the family, other care-givers and the clinical team and, if all are in agreement, recommend that treatment should be implemented (Stanley, *op cit.*, 131). Medical and legal professional organisations agree with these recommendations and add that, while a consensus between health professionals and the family is usually sufficient for less serious decisions, some treatment decisions are so serious that the courts may need to become involved in making the decision (BMA and The Law Society, 1995: Chapter 10).

Criticisms of the best interests standard are many and varied. It has been criticised for being paternalistic and more suited to decision-making for children than for adults, regardless of their decision-making capacity. While any treatment should be of benefit to the patient, it would be wrong to apply the standard without balancing different and conflicting interests (Kopelman, 1997: 283). Associated with being self-defeating, it is criticised for being too individualistic, demanding that only one person's interest is considered and unfairly ignoring other people's interests (*ibid*: 284). The next two criticisms go hand-in-hand; they state that it is ineffective to use the best interests standard because it is unknowable and vague. It is unknowable because no one can ever really be sure of another's best interests and the best that can be done is to maximise benefits and minimise harms in the choice of treatment. It

is criticised for being vague as it is often impossible to determine what values people judge as best. This is particularly true for the person who has left no indication, written or oral, of his or her wishes, preferences or desires with 'potentially conflicting values that are unstated, undefended and unranked' (*ibid*: 286).

The harshest criticism of the best interests standard is that it is too easily misused, dangerous and open to abuse (*ibid*: 285). There are fears that it will be used to withhold or withdraw treatment based on the decision that it would not be in the patient's best interests to continue to be treated.

Alternative Models of Decision-making

The "shared decision-making" model actively involves patients in their healthcare and is an important dimension of contemporary models of patient-centred care. There is concern among policy makers in the United Kingdom 'to equalise relationships between health professionals and lay people ... [with a] ... new emphasis on shared information, shared evaluation, shared decision making and shared responsibilities' (Williamson, 1999: 719). In shared decision-making there are two fundamental principles: promoting the patient's well-being and respecting the patient's autonomy. Brock (1998) describes the concept of well-being as being 'designed to signal the respects in which the fundamental goal of medicine is in part subjectively determined by the particular patients' aims and values' (*ibid* 232). The patient's autonomy reflects the patient's interest in making these treatment decisions for him or herself and being allowed to act on these decisions. In essence, shared decision-making is a combination of the substituted judgement and the best interests models with a heavily weighted subjective element: what is best for this particular patient subject to his or her personal preferences. Without an advance directive or some prior discussion with a proxy or doctor there may be difficulties determining what the best decision for the patient is in the circumstances.

In cases where neither substituted judgment nor the best interests are appropriate methods of making decisions and shared decision-making is also inappropriate, a fourth model of decision-making may be the answer. Deverette (1995) proposes a third "reasonable treatment" standard by which to make these difficult decisions. This could be used to justify withdrawal of treatment where there is no cogent reason

for continuing to treat the patient. Withdrawal of artificial nutrition and hydration for a patient in a PVS would, ostensibly be neither a benefit nor a burden and the reasonable treatment standard would justify withdrawal of all treatment with the ultimate consequence that the patient will die. Critics of this reasoning argue that the PVS patient has one interest – the interest to live and that this is enough to apply the best interests standard.

Deverette summarises the rationale of this type of decision-making by placing the different standards in a form of hierarchy. When patients have no decision-making capacity, someone else must decide for them, this could be an appointed proxy or the doctor in charge of medical treatment and care. The decision-maker would have a choice of three standards: first, to use the substituted judgement standard and report what the patients wants. If this is not possible, then the best interests standard would be used to try to decide what is in the best interests of the particular patient. If the patient has left no indication of his or her wishes and has no interests because of the permanent loss of all awareness, the decisions can only be made on the basis of what constitutes reasonable treatment in the circumstances (*ibid* 115).

Advance Directives and Decision-making

When making treatment decisions for patients without capacity, an advance directive may assist the proxy or healthcare professionals in formulating a treatment plan which takes the patient's wishes into consideration, thereby attempting to retain his or her individual autonomy. There are two main ways by which advance directives can aid decision-making: by acting as a catalyst for communication between doctor and patient, and as a tool to help the main actors in the decision-making process.

In a qualitative, ethnographic study of elderly patients in nursing homes in the eastern Netherlands, The *et al* (2002) found that doctors' decisions about care and treatment were influenced more by the clinical course of the illness, the presumed quality of life of the patient, and the patient's medical condition than by any advanced planning of care (*ibid* 1326). Patients' wishes were factors in the decision-

making process and a written advance directive influenced the doctor's decision to withhold the artificial administration of fluids and food (*ibid* 1330).

In a recent study of older people's views on advance directives in Britain, 82% of the participants had never heard of living wills, but (75%) would welcome the chance to discuss issues surrounding the end of life (Schiff *et al*, 2000: 1640-41). Unfortunately communication between doctors and patients about important treatment decisions is poor (Virmani *et al*, 1994: 913). Few doctors or patients initiate discussions on planning their future healthcare although doctors and patients did agree that it was up to the doctor to initiate the discussion (Emanuel, 2000; Morrison *et al*, 1994; Reilly *et al*, 1994).

Potential barriers to physician-initiated discussions were investigated by Morrison *et al* (1994). The main barrier to communication was the timing of the discussion: patients believed that the conversation should be initiated early in the doctor-patient relationship, while doctors believed the 'advance directive discussion should occur later in the physician-patient relationship, at an older age of the patient, and later in the course of the disease' (Johnston *et al*, 1995: 1028). Even when conversations do take place, there is little evidence that this makes much difference to ultimate treatment decisions, and there are few direct benefits (Foubister, 2001: 1). The indirect benefits are improvements in the relationships between patients and their doctors, 'if you talk to your patients about these things you fundamentally change the relationship that you have with your patients ... what they do is create an opportunity for me to sit down with my patients and have some really meaningful discussions about what they want done' (Tierney in Foubister, *ibid*: 1-2).

Advance directives can be used as a tool in the decision-making process, helping structure shared decision-making, 'not replac[ing] discussions about treatment and care, but guid[ing] them' (Widdershoven and Berghmans, 2001: 185). According to Brock (1998), when used alongside substituted judgement, advance directives can help to make healthcare providers respect the now incompetent patient's prior autonomy as much as possible (*ibid* 233). However, a recent study, which looked retrospectively at the effect of advance directives on the accuracy of surrogate

decisions, showed that there was 'no significant improvements in the accuracy of surrogate substituted judgement in any illness or for any medical treatment' (Ditto *et al*, 2001: 421). The researchers believed that their results challenged the conventional belief that advance directives are a means of honouring the patients' specific wishes when they have lost competence (*ibid*).

Clinicians' values inform their decisions even when a valid advance directive exists and where they disagree with the patients' wishes they may ignore the directive (Mower and Baroff, 1993: 380). One study emphasised the central role for clinical judgement in critical decision-making in interviews and focus groups with nurses and doctors in the west of Scotland. The conclusions reached were that advance directives were open to interpretation and that any particular outcome cannot be relied upon (Thompson *et al*, 2003: 1016). Significantly, a criticism of the substituted judgement model is also valid in relation to advance directives, as the decision-makers appear to be influenced by their own principles and beliefs and 'what some of the participants lacked was a willingness to step out outside their own value system in fully embracing that of the patient' (*ibid*). In a study of nursing home patients, 75% of the treatments received were consistent with the preferences expressed in the patients' advance directives. However, much of this consistency might be explained by shared values among doctors and patients (Orentlicher, 1992: 2101).

Conflicts

Medical decision-making was once a simple process: the patient put his or her life in the doctor's hands and the doctor in turn did the best he or she could to alleviate the patient's suffering and to prolong his or her life as long as possible. Medical paternalism meant that the doctor would decide what the best course of action would be to help the patient return to health, and disagreements were few because the doctor made decisions unilaterally. Conflict between doctor and patient occurs 'when the patient ... tries in some way to control what the physician does to him' (Freidson, 1975: 296). Criticism of this paternalistic behaviour has led to a support for the principles of patient autonomy and patient self-determination and giving the patient a

primary role in decision-making. According to Deverelette (1995), this situation leads to conflict because doctors cannot abdicate their responsibility for the medical treatment they provide for the patient. This has led to questions about the rights of doctors and to encouraging patients to think through treatment decisions for themselves and ‘in cases involving conflict of values, ... learn[ing] to decide what is the better course of action [in the circumstances]’ (Dewey, 1978: 10).

An early study of the prevalence of conflict during life-support decisions found that in 63% of the 400+ doctors and nurses conflict arose over decisions about life-sustaining treatment (Mulvihill, 2001). In 45% of cases, conflicts were centred on issues such as pain control and communication between healthcare staff and family members. Conflict occurred between family members and healthcare staff in about half of these cases, and just as frequently there was tension among staff members. In about one quarter of cases, family members had conflicts with each other. Another study examined compliance by doctors with patients’ wishes. The researchers found, that among 535 doctors in Sweden, Germany and Russia who participated in end of life decision-making, conflicts in decision-making were significantly reduced when more information was available about patients’ wishes, through “Do Not Resuscitate” orders and advance directives, highlighting the ‘usefulness of detailed patient directives’ (Richter *et al*, 2001: 190). Nevertheless, a relatively large number of doctors would not act according to the patients’ explicit wishes, especially in Russia. The researchers explain this in terms of ‘the conflict between the doctor’s and the patient’s autonomy and also between the doctor’s duty of beneficence and the patient’s autonomy’ (*ibid*).

Conflict between doctors and patients may be due to misperceptions and lack of awareness. Schneiderman *et al* (1997) investigated physicians’ predictions of patients’ preferences in treatment decisions and found that patients viewed their state of health in a better light than their doctors or their surrogates. Furthermore, doctors commonly misunderstood what their patients’ preferences and treatment wishes were, and importantly, were often unaware that their patients had executed advance directives to document their wishes (*ibid*, 135).

Solutions for dealing with these conflicts include anticipating tension-filled situations to prevent discord,

Keeping families informed about the patient's response to therapy and what treatment options remain throughout a patient's illness may reduce the likelihood that families will be blind-sided by a request to limit treatment. Family conferences are helpful, and just as there is constructive criticism, there can be constructive conflict. For example, when staff members disagree on the appropriate level of treatment, each side may have legitimate concerns that need to be addressed, and disagreement over decisions between the family and staff may reflect differences in values (Tulsky in Mulvihill, 2001: 283).

A study into conflicts between patients and their caregivers found that caregivers making surrogate decisions based on considerations of treatment outcomes might not effectively represent patients' preferences (Fried *et al*, 2003). When asked to rate physical states of health as being either acceptable or unacceptable, patients or their carers were at least 80% in agreement. However, patient-caregiver agreement about the acceptability of health states with functional or cognitive impairment was poor.

Conflicts between doctors and families are rarely resolved through recourse to law. Scots law is seldom used to intrude into the doctor-patient relationship and one of the reasons for this is the 'strong role that paternalism has traditionally played in the practice of medicine in Scotland,' with many people retaining the "doctor knows best" perspective regardless of the growing demand for greater patient autonomy (Miller and Meyers, 1992: 91).

Relationships and Trust

Doctors argue that the doctor-patient relationship is based on trust, but trust must be mutual. The patient must trust the doctor but there must be reciprocity in this relationship and therefore the doctor needs to trust his or her patients. This relationship, according to Leenen, would benefit from regulation, especially the regulation of the rights of the patient, something reflected in Dutch law in the law on medical treatment and in the European Convention of Human Rights, particularly in the case law of the European Commission and European Court of Justice. Moreover,

the 'movement of patients' rights can develop in an antithetical way if doctors oppose it and only defend their own position' (Leenen, 1992b: 106).

While Miller and Meyers (1992) believe that trust is the strongest factor in the doctor-patient relationship, paternalism is also an intrinsic element. The attitude of "doctor knows best" is reflected in the comment that

most patients, no matter how intense their desire to be informed of their condition and the available treatment options, deep down want to put themselves into the hands of their physician and to have him or her do what is "best" for them (*ibid*: 91).

The relationship that can develop between doctor and proxy decision-maker is an important one principally because the patient, due to his or her inability to participate in decision-making, relies on these parties to make the most appropriate treatment decisions in the circumstances. Unfortunately problems arise in these relationships through uncertainty about the duties and obligations of the proxy who is often ignored in the decision-making process; Dubler (1995) offers several reasons for this. The original case law on surrogate decision-making (*Quinlan*, 1976; *Saikewicz*, 1977; *Eichner*, 1981) sought to protect patients from the "wrong" decision being made by the proxy and attempted to produce legal standards with which to control choices. These were intended to protect patients from decisions which were made by self-interested surrogates who might make decisions not in the patient's best interests, with doubtful motives.

Deverette (1995) describes a different type of conflict that can exist in healthcare situations, the conflict between clinical and ethical goals. The clinical goal associated with healthcare decisions is to decide what will be good healthcare for the patient. In most cases this will be treatment to cure the disease and good patient care. However, this is not always the case. Sometimes good care can involve withholding futile treatments, palliative care for a terminal disease and generally recognising medicine's limitations. The risks associated with many treatments and surgical interventions, the unpleasant and often debilitating side effects of many medications and the need to justify these injurious features of good medical care are all areas that may conflict with the clinical goal of good healthcare. These potential conflicts are

some of the factors that give rise to the inherent complexity of decision-making in healthcare (*ibid*: 78-9).

Advance Directives and Conscientious Objection

The principle of autonomy is often referred to as a basis for recognising conscientious objection. While respect for autonomy is an important ethical basis for the patient's right to refuse treatment, it can also apply to the doctor and in asking them to carry out procedures with which they disagree, ignores their right of autonomy. However, Wicclair (2000) believes that there are several problems with this line of reasoning. First, only certain types of reasons (ethical or religious) are valid conscientious objections. Second, it is possible to respect a physician's conscience without respecting his or her autonomy –a doctor withdrawing from a patient's care because he or she does not agree with the patient's treatment choices is not the same as respecting the doctor's autonomy to determine the care a patient will receive. Finally, respecting a doctor's autonomy does not automatically provide a reason for believing that his or her choices are ethically acceptable but respecting a conscientious objection can influence the moral assessment of choices and actions. Wicclair explains this further by arguing that a doctor who refuses to participate in a patient's care through purely autonomy-based reasons could be subject to moral condemnation for that decision, while a refusal based on conscientious objection is likely to immunise the doctor from such condemnation (Wicclair, 2000: 212-13).

Rather than using respect for autonomy as a basis for recognising conscientious objection, Wicclair prefers the physician's stronger claim of respect for moral integrity and argues that appeals to conscience can be understood as efforts to preserve or maintain moral integrity' (*ibid*). Moral integrity, according to Wicclair, shows that the physician has core ethical values that are part of an understanding of who he or she is and therefore be incompatible with the requirement to participate in the patient's treatment choices in question. Nevertheless, it would be inappropriate for doctors to have a blanket right to use conscientious objection to enable them to withdraw from patient care without facilitating the provision of other treatment. This is why conscientious objection to certain treatments and procedures (e.g. termination

of pregnancy¹²) are usually kept in check through self-regulatory guidelines. The understanding that doctors can object in principle to advance directives is recognised in the BMA guidelines, which indicate that management of the patient can be passed on to a colleague (British Medical Association, 1995a: para 13.4, 35). Appeals to conscience by doctors can be accommodated by transferring the patient to a colleague, providing all parties are in agreement with this solution.

A more effective means to accommodate physicians' integrity interests without compromising patients' rights and patients' interests is for 'physicians to clearly inform patients *in advance* of any value commitments that will restrict the range of services that the physician is willing to provide' (Wicclair, 2000: 226-27, emphasis in original). The BMA (1993) advises its members to 'consider their own views and to inform patients at the outset of any absolute objection they have to limiting treatment; competent patients then have the opportunity of consulting another doctor or re-considering their own stance' (Stanley, 1989: 130). The obvious situation that comes to mind is that of the case of advance directives, where asking patients if they have an advance directive at the outset of their care allows doctors to identify one possible circumstance that may give rise to conscientious objection.

Rashid (2000) takes the issue of conscientious objection to advance directives further by suggesting that an element of reciprocity can come into play. Patients' rights to have their treatment wishes respected implies a corresponding right for healthcare professionals to have their moral, religious and personal beliefs respected and not to be pressurised into acting contrary to those beliefs: 'a patient's right of autonomy should not be purchased at the price of the physician's parallel right' (Beauchamp and Childress, 1994: 480). These rights will only be effective, however, 'if a substitute for the healthcare professional expressing a moral objection to carrying out the patient's wishes can be found' (*ibid*, 38). A solution to this dilemma reiterates the

¹² The UK Abortion Act 1967 has a conscientious objection clause which permits doctors to refuse to participate in terminations. The scope of the Act's conscientious objection clause was clarified in a Department of Health Parliamentary answer in 1991, and in a circular (Health Service Guidance HSG (94) 39).

In 1999, the BMA called on its Medical Ethics Committee to produce guidance on conscientious objections in relation to participation in termination of pregnancy due to the harassment of those doctors.

need to discuss these issues with patients in advance, opening up a dialogue between doctor and patient in terms of treatment decision-making.

Advance Directives and Advance Care Planning

Advance care planning offers patients an opportunity to gain control over their medical care if they ever lose decision-making capacity (Teno *et al*, 1994). Ideally this involves discussions with their medical practitioners resulting in a treatment plan for the future and documentation of their informed decisions regarding treatment if and/or when they become incapable or deciding for themselves (Teno *et al*, 1998).

Many advance directives have limited impact on decisions made for incompetent patients' medical treatment because they do not result from counseling and only contain vague instructions to physicians. Improvements in writing and implementing advance directives are needed if these instruments are to achieve their intended impact. These findings are based on the largest study carried out to date on the impact of advance directives on seriously-ill patients in hospitalised patients in the United States. The SUPPORT project - the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments – was a 10-year study of almost 10,000 inpatients at five teaching hospitals between 1989 and 1994 (Teno and the SUPPORT Investigators, 1995).

The goal of the study was to understand decision-making as it relates to the process of dying. It demonstrated that enhancing opportunities for more patient-physician communication alone was inadequate to change established practices or increase the uptake of advance directives or improve care and patient outcomes (*Ibid*. 1995; Teno *et al*, 1997a; Teno *et al*, 1997b). Many types of intervention and outcomes were studied including lack of clarity of advance directives, the quantity and quality of discussions with proxies and physicians, the disturbing experience of dying patients and their families and the importance of advance care planning in end-of-life treatments. The last years of the study followed implementation of the Patient Self-Determination Act, a federal statute aimed at ensuring availability and effectiveness of advance directives, including an effort to improve advance care planning for more

than half of patients by providing prognostic information and counselling by a skilled nurse. Even after passage of the Act, only 20% of patients had an advance directive. The researchers urge renewed focus on physician-patient communication and more comprehensive advance care planning (*Ibid.* 1995).

A study by the Agency for Health Care Policy and Research (1997) found that most written advance directives are too vague to make a difference in the patient's care. When the researchers reviewed the charts of 4,804 dying patients, they found only 688 written advance directives, of which, only three per cent (22) were specific enough to guide medical practitioners' decisions about a specified medical treatment. Among patients who had written advance directives, only about 1 in 10 had spoken with their doctors when writing the directive, less than half had ever talked with any of their doctors about having a directive, and only about one third had their wishes documented in their medical records. Even when specific instructions were present, care was potentially inconsistent in half of the cases and, furthermore, written advance directives did not reduce the use of hospital resources.

At the turn of the century further reviews showed that the take up of advance directives within the United States had not made much progress. Pollack (2000) shows that 90% still do not have advance directives and that little improvement has been made in discussions between doctors and patients about end-of-life issues with Medicare, insurance companies and hospitals doing little to remedy this. Pollack's conclusion is that this supports the case for listing simplified advance directives on the patient's Medicare card.

A study conducted in Hawaii (Braun *et al* 2001) found that 29% of Hawaii residents had a living will and 22% had a healthcare power of attorney. An analysis of a random sample of all US deaths in 1986 found that about 10% of decedents had living wills (Hanson and Rodgman, 1996) while more recent studies suggest rates of 15% to 25% among the general public (Miles *et al*, 1996). Compared with the US mainland, findings suggest that Hawaii has similar rates of advance directive completion in its general population, but higher rates of completion among adults age 65 and older (2001: 1710).

Fewer advance directives appear to be written in Europe. An investigation of attitudes towards writing advance directives in Germany found that 18% of cancer patients, 19% of healthy controls and only 10% of nursing staff had written an advance directive (Sahm *et al*, 2004). This was the first time such an investigation had been conducted in Germany and the researchers observe that the low rates of those who had written an advance directive corresponded with the results obtained through the SUPPORT study in different groups of patients and among nursing home residents (*ibid.* 439).

The highest level of advance directive completion and appointment of a proxy has been noted when associated with systematic and comprehensive implementation of advance care planning. In a study examining the effect of systematically implementing advance directives in nursing homes on patient and family satisfaction with involvement in decision-making and on healthcare costs, Molloy *et al* (2000) found that systematic implementation of a programme to increase the use of advance directives reduces the use of healthcare services without affecting satisfaction or mortality. Dr Molloy and colleagues introduced the “Let Me Decide” advance directive programme at three nursing homes. This included educating nursing home staff, residents and family members, and offering residents (or next of kin of mentally incompetent residents) an advance directive with a range of choices regarding treatment in the event of life-threatening illness or cardiac arrest. Ninety competent residents and family members of 305 incompetent residents completed an advance directive. The researchers suggest that the results may have implications for training of nursing home personnel and healthcare systems across Canada, the United States, and northern Europe may be sufficiently similar that the findings could be replicated in other countries (*ibid.* 1443).

In an editorial discussing the above study, Teno (2000) suggests that advance directives are not an end in themselves, but rather ‘they must be seen as part of the process that includes ongoing communication about the goals of care and the development of contingency plans that will ensure both that preferences will be honoured and appropriate palliation provided’ (*ibid.* 1481). Nevertheless, medical

decisions ought to reflect patients' informed preferences and values and the findings of Molloy *et al* suggest progress in these areas (*ibid.*).

As life expectancy has increased, so too have the multiple complications associated with chronic illnesses in the later years of life. Once the patient is unable to participate in decision-making it becomes essential that plans be made in advance to guide future decisions about medical treatments. Teno (1994) describes the goals of advance care planning to encompass the following:

1. Ensure clinical care is consistent with patient preferences when capacity is lost.
2. Improve the decision-making process through:
 - Facilitating shared decision-making;
 - Allowing the proxy to speak on behalf of the patient;
 - Responding with flexibility; and
 - Providing education.
3. Improve the patient's well-being by reducing the frequency of over or under treatment.
4. Reduce the patient's concern regarding any possible burden placed on the family or others (*ibid.* S32-36).

In a study to understand the role of written advance directives in medical decision-making through an examination of qualitative and quantitative data sources, Teno *et al* (1998) addressed the question of whether physicians unilaterally disregarded advance directives. The research showed that the effectiveness of advance directives could be improved by approaching advance directives more as dynamic processes of communication and negotiation about the goals of care rather merely formal legal documents (*ibid.* 445). The overall conclusions were that physicians did not unilaterally disregard patients' advance directives. The two factors that enhance the role of the directives were surrogates who were available to advocate for the patient and open communication between the physician and the surrogate (*ibid.* 445-6).

Finally in an editorial written in 2004, Teno comments on the 'striking increase in the use of written advance directives'. From a report of a 22-state survey of bereaved family members Teno and her colleagues estimated that 71% of persons dying in those states had completed an advance directive before death (2004). Teno argues

that increasing the use of advance directives is important, but cautions that they are not sufficient to address the concerns of family members of dying patients.

Improving the quality of end-of-life care requires moving from a focus on single interventions, such as the living will, to a focus on public policies that use multifaceted interventions to provide competent, coordinated, and compassionate end-of-life care (2004: 160).

Justice

The fourth *prima facie* moral principle is justice. This places a moral obligation on all persons to act justly or fairly towards others in the context of respect for each other's rights, in the distribution of scarce resources, and in the context of obeying morally acceptable laws (Stanley, 1989: 130). Justice can be subdivided into three further categories: rights based justice; distributive justice; and legal justice.

Advance Directives and Human Rights – Rights Based Justice

The right to refuse treatment while competent is not in dispute and is authorised by case law in the UK (see Chapter One) and by statute (WGB0) in the Netherlands'. In respecting an individual's autonomy the person's right to refuse treatment while competent continues when he or she becomes incompetent if instructions have been left in a validly executed advance directive. In considering treatment for patients without capacity, the BMA (1995, 10:4) have devised some general principles which constitute best practice. The patient has several rights, these include:

- Freedom from discrimination – the patient should not be treated differently solely because of the condition that gives rise to his or her incapacity;
- Privacy and freedom from medical procedures unless there are good therapeutic reasons for them;
- Confidentiality – his or her personal information should not be disclosed unless necessary;
- Liberty – the patient should be free from interventions that inhibit liberty or the capacity to enjoy life unless necessary to prevent greater harm to the patient or to others;
- Dignity – social and cultural values should be respected; and
- Participation – the patient's views should be taken into account even if he or she is considered legally incapable of determining what happens regarding his or her treatment.

Incorporation of the European Convention on Human Rights into UK law confers a responsibility on governments to ensure that individual rights are not violated through legislation or otherwise. The right to life expressed in Article 2 of the ECHR is an area that may be addressed in relation to recognising a refusal to accept medical treatment. Human rights organisations believe that this is an area for specific legislation and do not consider Article 2 to be fundamentally incompatible with possible future legislation on advance directives (Liberty, 1991). The passing of the Human Rights Act 1998 may mean that human rights arguments will be advanced to justify the legality of advance directives (Laurie, 2001: 36). Article 3 (inhuman and degrading treatment) may be useful to persons trying to safeguard their personal autonomy in the shape of an advance statement.

A society that is seriously committed to the principle of self-determination gives rise to an expectation to give legal effect to advance care planning (Teff, 1994: 143). At present patients have no guarantee that their wishes will be respected and doctors may find themselves facing a dilemma between respecting a patient's advance wishes and acting as they see fit. The current solution in the UK in particular the,

absence of legislation and the fact that the case law is only now tentatively addressing the issue is a further illustration of the gap between long-standing rhetorical endorsement of self-determination and concrete provision for it (*ibid*, 146).

Legislation, however, may lead to an increase in confrontation between doctors and patients and a possible move towards greater litigation (*ibid*, 170).

As a footnote to rights-based justice, the antithesis of the right to refuse treatment when incompetent would be the right to consent to treatment in a similar way. In a challenge to General Medical Council (GMC) guidelines, Leslie Burke won the right for treatment not to be withdrawn against his wishes when he could no longer communicate. Due to a progressive condition, Mr Burke is likely to require artificial nutrition and hydration in the future and GMC guidelines meant that doctors could make a decision to withdraw artificial feeding if they believed that further treatment was futile. Mr Burke argued that existing guidance provided to doctors by the GMC contravened his right to life under the Human Rights Act 1998. Agreeing with Mr

Burke, the High Court ruled that the GMC guidelines would have to be redrafted (*R (on the application of Oliver Leslie Burke) v. The General Medical Council* 2004). The Disability Rights Commission wants the guidance about “quality of life” to be removed from the guidelines as there is too much scope allowed for a doctor’s personal opinion to influence the outcome of a decision about providing artificial nutrition and hydration (Adam-Spink, 2004). This is a groundbreaking case, as it recognises the ability of competent patients to require the establishment and continuation of life-prolonging treatment in certain limited circumstances, whether done contemporaneously or via an advance directive (Commentary, 2004: 315).

Advance Directives and Resources – Distributive Justice

The principle of justice requires ‘universal access to an acceptable, decent minimum of basic health care’ (Stanley, 1989: 133). In the context of the allocation of medical resources, conflicts exist between several common moral concerns. According to Gillon (1994), medical professionals should,

... meet the needs of all who require it; when this is impossible, to distribute healthcare resources in proportion to the extent of people’s needs for healthcare ... to allow people as much choice as possible in selecting their healthcare [and] to maximise the benefit produced by the available resources ... (*ibid*, 183).

The Appleton Consensus (1989) agreed that the principal task of the clinician was to

assess other competing values and to make judgements about which healthcare needs are most pressing and which responses to those needs are reasonable and proportional (*ibid*, 133).

As ever-increasing costs for healthcare generate greater demands on scarce resources and since the 1990s there has been an increasing emphasis on reducing costs in healthcare. Medical ethicists have become ‘concerned about the potential for conflict between the desire to hold down costs and the duties of health-care providers to act as strong advocates for those in their care’ (McGhee and Caplan, 2000: 3).

Critics of advance directives have pointed out that they may be a way of saving money. Teno’s (2000) query of whether promoting the completion of an advance

directive saves resources otherwise squandered on care not wanted by the dying patient remains a tantalising question. However, serious problems would occur if they were seen as a covert measure for reducing treatment costs or limiting the amount of care given to the elderly and the terminally ill. If this were the case then support for advance directives by healthcare staff could arouse suspicion and create mistrust (Sommerville, 1996a). A study of the relationship between advance directives, hospital charges and patient autonomy indicated that they were regarded in a more positive light. In a survey of 474 patients over a period of three years Chambers *et al* (1994) found that during discussions of advance directives, patient often opted to limit the extent of care they required in certain situations. The results imply that ‘an enormous cost saving to society may be realised if such discussions take place, while, at the same time, autonomous patient choice will be respected’ (*ibid*, 541).

Advance Directives and the Legal Profession – Legal Justice

Until the 1960s and the development of bioethics or health law, medical ethics was the ethics of good medical practice, doctors were expected to act for the good of the patient and specific rules of health law were virtually non-existent. The law respected professional autonomy and upheld extensive discretionary powers for doctors and only marginally interfered with medical practice (van der Burg, 1997: 95). Since these developments, little further has been done in either Scotland or England and Wales on a statutory front to emphasise patient self-determination, with only a consideration of respect for a person’s present or past wishes in section 1 of the Adults with Incapacity (Scotland) Act 2000 and with no legislation as yet in England. While speaking primarily of the law surrounding “allowing to die”, Lord Browne-Wilkinson addressed the problem as follows:

Should judges seek to develop new law to meet a wholly new situation? Or is this a matter which lies outside the area of legitimate development of the law by judges and requires society, through the democratic expression of its views in Parliament, to reach its decisions on the underlying moral and practical problems and then reflect those decisions in legislation? I have no doubt it is for Parliament, not the courts, to decide the broader issues which

this case raises (*Airedale National Health Service Trust v. Bland* [1993] 1 All ER 821 at 878, HL).

The authority of doctors and judges to make the ultimate decisions in these matters encroaches on the autonomy of the patient and extends from “allowing to die” decisions to treatment decisions as a whole. English judges have traditionally favoured the “best interests” test, which can be used to restrict patient autonomy in favour of medical paternalism (Morris, 1996). This test was also used by the Scottish courts in a case (*Law Hospital v. Lord Advocate and Others* (1996) 39 BMLR 166) where the courts were asked to reach a decision about whether it would be unlawful to withdraw artificial feeding from a woman in a permanent vegetative state. By ruling that this would not be unlawful, the court applied a best interests test in holding that further treatment would not be of benefit to the patient. However, as McLean observes, the crux of the diagnosis was that the patient had no interests and it was therefore impossible to decide whether the test had been met (McLean, 1996: 262).

Much UK case law has seen the judiciary ‘pass the parcel of patient rights to the medical profession, and so “by-pass” the central tenet of medical law, namely self-determination’ (Laurie, 2001: 32). Many judges in England ‘have tended to hide behind “clinical judgement” in cases which involve questions of medical treatment’ (Stern, 1994: 70); for example, according to Stern, the real question in *Bland* (*Airedale NHS Trust v. Bland* [1993] AC 789) was whether Tony Bland should be kept alive and not whether the medical treatment he was receiving (artificial nutrition and hydration) was effective in achieving this end.

The deference the law (at least in Scotland) pays to the medical profession in respect of patients’ rights is felt by Laurie to be characterised by:

- Grudging acceptance of the right to self-determination, including the right to refuse treatment;
- Dominance by the ‘best interests’ test where patient competence is in doubt;
- Undue deference by the courts to the medical profession to determine what should be meant by ‘best interests’;
- Serious reluctance on the part of the courts to intervene in the assessment of best interests; and

- Perhaps most surprisingly of all, the willingness of the courts to surrender to the medical profession the responsibility for determining the scope of the duty of care to patients, and the linking of this assessment with the assessment of patient best interests (*ibid*, 7).

The English Courts have been accused in the past of being too deferential to the medical profession in the past, but this has come to an end with a 'move to a rights based society [which] had fundamentally changed the behaviour of the courts' (Dyer reporting Lord Woolf, 2001: 129). It appears that the 'automatic presumption of beneficence' (*ibid*) afforded to doctors by the courts has come to an end

Gillon (1994) states '... even if a person believes that the law is morally unjustified, there is no *legal* entitlement to break the law and no justification to avoid the consequences of doing so' (*op cit.* 185). A dilemma occurs when there is no clear statute setting out the rules to be followed in a particular situation. This dilemma is present in the use of advance directives and much attention has been given to their legal status in the UK. The legal profession has a degree of authority in this matter; while at the present there is no precise wording required in drawing up an advance directive, expert drafting can only help ensure that healthcare professionals comply with it. The question of whether a solicitor, in the absence of any legislation, is legally obliged to inform a doctor that the patient has an advance directive may also be raised (Mason & McCall Smith, 1999: 338).

Summary

Professional autonomy gives the medical and legal professions freedoms in many if not all of their working practices. They enjoy a monopoly in their specialised work and expect non-interference from outside agencies. Although this all contributes to their professional power, professional autonomy may be being eroded by an increase in individual autonomy, by further internal and external controls over professional activities and by greater governmental involvement in setting standards and guidelines, especially in relation to healthcare.

Individual autonomy is associated with agency and an individual's entitlement to make his or her own decisions and formulate his or her goals. Autonomy for the

individual patient is often in conflict with professional medical autonomy and sometimes leads to an erosion of trust in medical decision-making. However regardless of an increase in individual autonomy and a continued wearing down of professional autonomy, most authors agree that professionals still exercise more power than the individual client in law, and considerably more than the individual patient in medicine.

Bioethical principles are well-established and are useful in informing medical decision-making in the area of incompetency. Advance directives, as a tool for extending patients' autonomy into the future, have, in the last decade, raised serious issues of respect for individual and professional autonomy, personhood, and justice in the medical, nursing and medico-legal literature. The idea of using anticipatory decision-making as a method of extending personal autonomy into the future has been welcomed by a majority of healthcare staff but a significant minority has had serious doubts as to their efficacy and raised objections based on conscientious grounds. Further disagreement is apparent in the debate concerning their legal status, where opinion is divided.

Chapter Three Methods

Introduction

This chapter describes the methodology used in this thesis and contains a discussion of the issues involved in the research. First, the aims of the research and how these informed the choice of research questions are examined. This is followed by discussions in which use of the interpretive paradigm, case studies and qualitative research methods are considered. The following section deals with the research methods employed in this study and details the information that was required and who could provide it; the preparatory work completed before data collection was started; and what problems were anticipated and encountered in obtaining this data. The data collection methods are discussed along with a consideration of the research ethics involved. How the data was analysed concludes this chapter with a brief summary of the main points at the end.

Aims of the Research

As stated in Chapter One, discussion of living wills or advance directives focuses on respect for autonomy. Many healthcare professionals have welcomed using these devices as methods of extending personal autonomy into the future but the directives may produce concerns when the professional's (most likely the doctor's) treatment decisions are at odds with those stated in an advance directive. This has led to a significant minority expressing serious doubts as to the efficacy of the advance directive in preserving individual autonomy, especially where this may conflict with the doctor's professional autonomy and inherent professional power.

Disempowerment encountered by patients and their families who have cause to be come involved in the healthcare system often arises from a lack of knowledge and ability to assert their wishes. Healthcare professionals often must make decisions concerning treatment for persons who have lost the capacity to give or refuse consent without any clear indication of the person's wishes. Relatives may have an idea of what that person would have wanted, in such circumstances, but in the UK they

cannot give consent to or refuse treatment on their relative's behalf and only a statement made by the patient setting out what he or she would wish to consent to may be a way of preserving the patient's autonomy. A document setting out that person's wishes can help treatment decision-making for the clinical team and the family and may allow the doctor to apply a model of decision-making more in line with substituted-judgement rather than the more paternalistic "best-interests" model.

Conversely, the ultimate decision-making power of the physician may be affected by an advance decision made by the patient and this may cause conflict between professional autonomy and individual autonomy. Earlier research for an MSc dissertation (Anderson, 2000) provided an insight into the policy processes involved in decision-making for incapacitated adults, and as such forms a useful background to this research which focuses on the decision-makers themselves: medical practitioners, patients and their legal representatives. The ultimate aim of this research – ascertaining how advance directives impact on professional and individual autonomy and the balance of power between doctor and patient – was achieved exploring the process of decision-making concerning medical treatment for patients without capacity, discovering whether doctors take advance directives into consideration when making treatment decisions for *incapax* patients and the ways in which those most involved assess the adequacy of the present legal arrangements. These aims give rise to the research questions outlined below.

Research Questions

Clarifying the type of research questions to be investigated - who, what, where, how and why questions - assisted in refining which research strategy to employ. If "what", "who" and "where" questions are the focus then they are exploratory and depending on the form of the question, all five strategies identified by Yin (1994) could be used, though surveys or analyses of archival records are used most often. "How" or "why" questions are explanatory and preferred research strategies are experiments, histories and case studies according to Yin (1994). Marshall and Rossman (1989) have prepared a matrix that explains the type of research question, the research strategy and data collection techniques for the different purposes of a

study, this has been adapted to incorporate the data required in this research and show how it fits into the matrix below (Table 3.1).

3.1 Matching research questions with research strategy

<i>PURPOSE OF THE STUDY</i>	<i>RESEARCH QUESTIONS</i>	<i>RESEARCH QUESTIONS ADAPTED FOR THIS STUDY</i>	<i>RESEARCH STRATEGY</i>	<i>EXAMPLES OF DATA COLLECTION TECHNIQUES</i>
EXPLORATORY To investigate little understood phenomena. To identify and/or discover important variables. To generate hypotheses for further research.	What is happening in this social programme? What are the salient themes, patterns, and categories in participants' meaning structures? How are these patterns linked with one another?	What are the issues surrounding treatment decision-making for persons without capacity? What are the significant techniques used in each of the cases in question? How do they link/compare with one another?	Case study Field study	Participant observation In-depth interviewing Elite interviewing
EXPLANATORY To explain the forces causing the phenomenon in question. To identify plausible causal networks shaping the phenomenon	What events, beliefs, attitudes, policies are shaping this phenomenon? How do these forces interact to result in the phenomenon?	What models of decision-making shape this phenomenon? What rules or laws determine the procedures executed? How do these models and rules interact in the cases?	Multi-site case study History Field study Ethnography	Participant observation In-depth interviewing Survey questionnaire Documentary analysis
DESCRIPTIVE To document the phenomenon of interest	What are the salient behaviours, events, beliefs, attitudes, structures, and processes occurring in this phenomenon?	What significant factors occur in the interaction of professional and personal autonomy?	Field study Case study Ethnography	Participant observation In-depth interviewing Documentary analysis Survey questionnaire
PREDICTIVE To predict the outcomes of the phenomenon. To forecast the events and behaviours resulting from the phenomenon	What will occur as a result of this phenomenon? Who will be affected? In what ways?	What might occur if advance directives were used more frequently in each of the cases?	Experiment Quasi-experiment	Survey questionnaire (large sample) Kinesics/proxemics Content analysis

(Source: adapted from Marshall and Rossman, 1989: 78)

Treatment decision-making processes used by healthcare professionals were useful models in examining professional autonomy and doctors' attitudes towards advance directives as part of this process. Documentary analysis established the legal regulations surrounding treatment decision-making for persons with or without capacity in each of the three jurisdictions. Then doctors and lawyers were asked a series of interview questions to discover the policy and procedures adopted during decision-making and their attitudes towards them, including the types of decision-making models used by doctors in deciding treatments for patients without capacity. Challenges to doctors' autonomy and how conflicts between families and clinicians are resolved were also investigated. Lawyers were able to provide data on the circumstances in which the parties in medical decision-making seek legal advice, however, in all three jurisdictions, it was clear that lawyers often made aspirational statements about how the law ought to be and referred less frequently to how the law actually works in practice. The last three research questions refer explicitly to advance directives - doctors and lawyers were both able to give their opinions on the legality of advance directives and these were compared with documentary evidence from statute and case law of their actual legal status. Finally, attitudes towards advance directives, medical decision-making and professional and personal autonomy were investigated in order to answer questions four and five. The research questions, which were set out on page 5, are reproduced below.

Research Question One

How is medical decision-making carried out, and how does this relate to statute or common law provisions in the three jurisdictions?

Research Question Two

What are the processes of treatment decision-making for *incapax* patients and how are they related to doctors' professional autonomy?

Research Question Three

How do doctors and lawyers view the current legal status of advance directives in each of the jurisdictions?

Research Question Four

Do doctors consider advance directives when making treatment decisions for *incapax* patients?

Research Question Five

How do advance directives affect professional and patient autonomy and the balance of power between doctor and patient?

Research Design

The Interpretive Paradigm

Research into healthcare situations often uses methods within the interpretive paradigm to allow comparison between different approaches to decision-making or treatment; between different sites where an intervention is taking place; and between different spheres of regulation of practice (Keen and Packwood in Pope and Mays, 1999). The interpretive paradigm is not a single approach to research and it brings together differing strands united by a phenomenological slant. Moreover, as a set of overarching and interconnected assumptions about the nature of reality (Maykut and Morehouse, 1997), and their normative nature, it is instrumental as a way of breaking down the complexity of the real world. Understanding of the real world is best achieved through observation, listening, asking questions, recording and examining. The design of this research is takes into consideration the need to balance the necessity for collecting unbiased data with the methods employed in obtaining that data, for this reason, the interpretive paradigm would appear to be an appropriate model for research on autonomy and decision-making. Its unique strengths lie in the value it places on context and setting and the 'search for a deeper understanding of decisions made by participants, and their lived experiences of the phenomenon' (Marshall and Rossman, 1995: 39).

Case Study Research

In considering case studies as a research methodology, I reviewed how to best answer research questions. As the nature of this research is mainly exploratory, the case study approach, involving qualitative methods of data collection was considered to be the most appropriate. Many interventions in the healthcare setting depended for their success on the involvement of several different interested parties, so it is often necessary to be sensitive to issues of collaboration and conflict: each party may have

a legitimate, but different, interpretation of events. The strength of good case study designs is that they can cope with, and provide insights into, complex real world developments, with the “case” providing a source of explanations for wider developments (Keen and Packwood, 1999). In this study, capturing the differing views of doctors and lawyers was felt to be best achieved using qualitative methods within a case study design.

Yin (1994) defines the case study method as an empirical inquiry that investigates a contemporary phenomenon within its real-life context; when the boundaries between phenomenon and context are not clearly evident; and where multiple sources of evidence are used (*ibid*, 23).

Yin adds that a case study design has five components: the research question(s); its propositions; its unit(s) of analysis; a determination of how the data are linked to the propositions; and criteria to interpret the findings. The three countries investigated within this research comprise the cases: the Netherlands, Scotland and England and Yin’s case study criteria are satisfied in the following manner. The research questions¹³ are concerned with how medical decision-making is carried out; how decision-making is affected by the medical profession’s authority; and the effect of advance directives on the decision-making process. Answers to the research questions were obtained through ‘conversations with a purpose’ (Burgess, 1991: 102), with the appropriate persons about their approaches to their professional roles, using qualitative research methods and adopting an interpretive and holistic perspective.

The propositions linked to the data are that greater regulation of medical decision-making achieves a more equal balance in power between doctor and patient and that advance directives can be used as a means of giving substance to the regulations. According to Brownell (1995) the units of analysis are the cases themselves, ‘as opposed to the multiple individuals, situations, places and contexts which may be implicated in a single case’ (*ibid*, 64). In this research the cases are the countries being investigated, each of which was analysed by conducting qualitative interviews

¹³ These are discussed in greater detail later in this chapter.

with doctors and lawyers and by studying documentation relative to the regulatory process. This included statute and case law, consultation and policy documents, and scholarly publications of a discursive and evaluatory nature on the current legal arrangements in each of the countries in question. The data were linked through the three methods of regulation¹⁴ of medical decision-making, in general, and advance directives in particular, in each of the three cases/countries and the ultimate comparison of these rules. Finally, interpretation of the findings was informed by the extensive literature reviewed on the fundamental principles of medical bioethics¹⁵, and the documents that were analysed prior to commencing fieldwork. The first four criteria are discussed in greater detail within this particular chapter, the fifth criterion is examined in Chapter Seven in discussion of the research findings.

Qualitative Research Methodology

Much research into the work of healthcare professionals involves interpretation of decision-making using methods that are qualitative rather than quantitative in nature; a tradition maintained by regular case study reports in leading medical journals (Keen and Packwood, *op cit*). Qualitative research methods adopt a subjective and holistic perspective, and by using methods of data collection such as in-depth interviewing, rich and varied data can be gathered (Bulmer, 1986). In addition, questions about behaviour, what people think and feel, about beliefs and attitudes are most successfully approached through face-to-face interviews. Asking participants about their experiences, within their own in work settings, can provide rich data for descriptive and explanatory accounts of organisational processes, work practices, and the impact of decision-making practices.

Case studies employing qualitative methods have been used by bodies that regulate public services, examples include the work of the National Audit Office (NAO, 1998) and the Audit Commission (1997) in the UK. They have also been used in evaluations, including studies of the introduction of general management (Pollitt, *et al*, 1988) and business process re-engineering (Packwood, *et al*, 1998) in hospitals,

¹⁴ Statutory Law (Netherlands); implied legislation/general principles of statutory law (Scotland); common law (England).

¹⁵ See Chapter Two

and of general practice fund holding (Laughlin, 1997) in the UK. All used one or more qualitative methods including interviews, documentary analysis and non-participant observation of meetings.

Validity and Reliability

Many qualitative researchers emphasise validity rather than reliability; documenting what occurs in an accurate manner may reveal inconsistencies, whereas reality is dynamic, changing constantly. Low reliability could be consistent with high validity if the social situation is continually in flux, or people might see things differently because they are seeing different aspects, different levels, and different perspectives of the whole which is far more complex than any single perspective/person might see. Putting two different accounts together might result in a better understanding of the whole than either one separately, even though the consistency between those accounts might be rather low. Together, the two very different accounts, reflecting low reliability, could produce even higher validity (Ratcliff, 1995).

For qualitative researchers, reliability in a form recognised in quantitative research is impossible to realise because the research design is so flexible and the research findings are produced by constantly changing interactions between researchers and participants (Oka and Shaw, 2000). As Guba and Lincoln (1989) state, “such changes and shifts are hallmarks of a maturing and successful inquiry” (*ibid*, 242). In this research, interviews were in a semi-structured form and as such facilitated consistent and reliable data analysis.

The concept of validity can be described by a wide range of terms in qualitative studies, not as a single, fixed or universal model, but “rather a contingent construct, inescapably grounded in the processes and intentions of particular research methodologies and projects” (Winter, 2000: 1). Although some qualitative researchers have argued that the term validity is not applicable to qualitative research, they have realised the need for some kind of qualifying check or measure for their research (Golafshani, 2003). Validity in qualitative research can be found through several methods: divergence from initial expectations by consulting personal notes; convergence with other sources of data by using a variation of triangulation

and comparisons with the literature; extensive quotations from field notes, transcripts of interviews, other notes; and other research data, such as archival data, recordings (video or audio). Within this research, validity as a check of quality was achieved through all of the above methods. Notes were taken during or more usually, immediately after data collection in the form of interviews. These notes complemented the interview transcripts when they were analysed using a qualitative data analysis computer package (NVIVO). Triangulation was employed through use of qualitative interviews and documentary analysis of policy documents, consultation papers and texts of statutes and governmental papers. Additionally, extensive quotations were used from interview data which was transcribed by an independent person in order to reduce interviewer bias in process of transcribing. Quotations from relevant regulations and guidance documents were also used to support and check the primary data.

Research Methods

Two contrasting types of autonomy are relevant to this study: professional autonomy and personal autonomy. Respect for autonomy was assessed through an investigation of the decision-making processes and by questioning how the current legal arrangements assist in protecting autonomy from both professional and personal standpoints.

Documentary Information

Documentary analysis was the first step in this research: it provided a basis for further investigation and freed up time to use other research methods as a means of discovering answers to questions not readily found elsewhere. Documentary analysis of the current legislative arrangements clarified each country's position in terms of legislation and case law. In the case of the Netherlands, the Act on the Medical Services 1995 and the debates that surrounded the passing of the Act were examined. Dutch legislation is published on an English language website and English is widely spoken in the Netherlands so few language problems were anticipated. Two months were spent in the Netherlands and this optimism was proved to be correct. The Dutch situation provided a basis for comparison with the Scottish and English positions.

Legislative arrangements in both Scotland and England were already partially addressed in my MSc dissertation (Anderson, 2000), which sought to demonstrate how government thinking developed and changed in the process of consultation. Further policy issues were investigated through the analysis of new documents, and of national and international case law. The documents analysed include:

In the Netherlands:

- The Law on Medical Treatment Contract 1995
- Review procedures for the termination of life on request and assisted suicide and amendment of the Criminal Code and the Burial and Cremation Act (Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001)
- Dutch Criminal Code

In Scotland:

- Scottish Law Commission Discussion Paper: *Mentally Disabled Adults*, 1991;
- Scottish Law Commission Discussion Paper: *Disordered and Vulnerable Adults*, 1993;
- Scottish Law Commission Report: *Incapable Adults*, 1995;
- Scottish Office Consultation Paper: *Managing the Finances and Welfare of Incapable Adults*, 1997;
- Reports, written and oral evidence of the Justice and Home Affairs and the Health and Community Care Committees of the Scottish Parliament, 1999;
- Scottish Executive Policy Statement: *Making the Right Moves*, 1999;
- Scottish Executive, *Millan Committee on Review of the Mental Health (Scotland) Act 1984*, 1999;
- Scottish Executive, *Millan Committee on Review of the Mental Health (Scotland) Act 1984*, 2000;
- Scottish Executive, *New Directions: Report of the Millan Committee's Review of the Mental Health (Scotland) Act 1984*, 2000;
- Adults with Incapacity (Scotland) Act 2000; and
- Mental Health (Care and Treatment) (Scotland) Act 2003.

In England and Wales:

- European Convention on Human Rights and Fundamental Freedoms 1950;
- Law Commission Discussion Paper: *Mentally Incapacitated Adults & Decision-Making: An Overview*, 1991;
- Law Commission Discussion Paper: *Mentally Incapacitated Adults & Decision-Making: Medical Treatment & Research*, 1993;
- House of Lords: *Report of the Select Committee on Medical Ethics*, 1994;
- Law Commission Report: *Mental Incapacity*, 1995;

- Lord Chancellor's Department, Consultation Paper *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults*, 1997;
- European Convention on Human Rights and Biomedicine 1997;
- Human Rights Act 1998;
- Government Policy Statement: *Making Decisions*, 1999;
- Hague Convention on the International Protection of Adults 2000; and
- Draft Mental Capacity Bill.

In Europe:

- RECOMMENDATION R (99) 4 of The Committee Of Ministers on Principles Concerning The Legal Protection of Incapable Adults (Adopted by the Committee of Ministers on 23 February 1999, at the 660th meeting of the Ministers' Deputies)

In addition, published speeches, parliamentary debates, and draft legislation, press releases, newspaper and journal articles relating to the above legislation and legislative proposals were reviewed. These documents were examined to identify the arguments for and against advance directive legislation and to show how ideas developed and changed in the process of consultation. This informed the interview schedules for both doctors and lawyers in the respective countries.

Case Law

A review of reported cases in Scotland and England and Wales was undertaken to inform the subsequent research. It was necessary to examine what the current state of the law is prior to asking respondents what they thought of it in interviews. In addition to UK case law, European case law, and applications presented to the European Commission of Human Rights and the European Court were also examined. Little case law on advance directives and medical decision-making exists in the Netherlands.

Preparatory Work

Earlier research carried out for my MSc dissertation (Anderson, 2000) attempted to the following questions:

- (i) Why did the UK government and the Scottish Executive decide not to legislate for advance directives in the light of the recommendations of the two Law Commissions and the Lord Chancellor's assurance that they would do so?

- (ii) Have the UK Government and the Scottish Executive yielded to lobbying by pressure groups that oppose legalising advance directives on the grounds that they are the first step towards legalising euthanasia?

It concluded that lack of clarity about the status of advance directives throughout the UK led to them being placed on the legislative agenda. However, the strength of feeling by those who were opposed to legislation and the ambivalent reactions of those who were in favour caused the Scottish Executive to have second thoughts. This, combined with political considerations in one of the first Bills to pass through the new Scottish Parliament, led the Executive to make a decision that was intended to minimise conflict by dropping the issue from the Bill. Lack of time in the UK Parliament at Westminster meant that incapacity legislation, which incorporated advance directives, made little progress until recently. As a result, advance directives still suffer from vagueness and lack of direction in legislative terms. In Scotland, the Adults with Incapacity (Scotland) Act 2000 makes implied reference to them in its general principles as taking a person's past and present wishes into consideration when making decisions in the face of his or her incapacity. In England at present advance directives are regulated by common law; by contrast, in the Netherlands statutory rules govern advance directives¹⁶.

Development of data collection instruments

Developing the research questions was a very challenging part of the project and much discussion and thought took place before deciding on the 'final' version. Initially the questions arose from the research undertaken for my MSc dissertation (discussed above) and further reading stimulated more questions with one question leading to others.

Many questions emerged from the aims which informed the research, especially those surrounding decision-making models and the possibility of competing autonomies. My interest in how people behave in providing care for the incapacitated – professionals, patients, families – shows that people relinquish their autonomy very easily especially when they are already vulnerable. I was interested in retaining my

¹⁶ Reports of medical bodies are also important in Dutch Law.

own autonomy, and was interested in whether there were others who felt the same and if so, how could autonomy be retained? Advance directives can be frightening but how do doctors feel about them? Very little research on this subject had been done in Scotland, and I felt that there was much to be learned from research, in particular from research which compared the position in Scotland with that in other countries.

During my previous career in psychiatry I had encountered both more and less impressive examples of ways in which medical practitioners made treatment decisions. In some circumstances anything that came between the doctor and his or her decision-making was seen as an obstacle and interference to effective treatment. In others, doctors welcomed patient involvement in the decision-making process and, of course, there were numerous variations between these extremes. Advance directives could have been welcomed or ignored, given passing regard or taken seriously as a decision-making tool. My experience also told me that, while the subject could have been explored through a survey, interviews were a better way of eliciting information from doctors. My knowledge of medicine and my familiarity with medical vocabulary gave me the confidence to engage in face-to-face discussion with doctors. My qualification in Scots law likewise contributed to any confidence in carrying out interviews with lawyers.

The subjects I wished to explore were grouped into topics and themes and divided into major and subsidiary questions which sought to address the five main research questions set out on pages eight and 83 above. It was always an option to alter the interview questions as the research progressed and this did happen following my first interview with a Scottish doctor prior to embarking on fieldwork in the Netherlands. Following my first interview with a doctor in the Netherlands, it became obvious that some of the questions that might be appropriate and relevant in the UK turned out to be less important or even inappropriate in the Netherlands and the interview schedules were altered accordingly.

The style of interview schedule was also developed through my knowledge of medical practitioners and application of that knowledge to lawyers. I anticipated

(correctly) that both doctors and lawyers would be less comfortable with a completely unstructured interview and would be happier if I used a semi-structured format to the interview. This was adapted during the interview with some interviewees happy to let the subject take its own course while others were more comfortable with a more straightforward question-and-answer format. The semi-structured format was also useful in keeping the interview on course and within the agreed time limit, something that was important for doctors and lawyers in all three jurisdictions.

Data Collection

In deciding to choose qualitative methods, the nature and sensitivity of the topic and the type of participants involved were taken into consideration. The next section discusses the methods used: who and what provided the data; how interviewees were selected; the following section describes how the data were analysed.

Blaikie (2000), states that there is no necessary connection between the type of research method used and the type of sample but 'because qualitative methods are resource-intensive, smaller samples must be used' (*ibid.* 203). This view was considered in devising the sampling strategy. How medical decision-making and the law work were elicited through in-depth interviews with doctors and lawyers in each of the three countries.

Research was carried out in three locations: the Netherlands, Scotland, and England, on a sequential basis. These locations were chosen because of the differences in legal arrangements for advance directives. In the Netherlands recent legislation¹⁷ had been passed giving a statutory basis to advance directives. In recent Scottish legislation (The Adults with Incapacity (Scotland) Act 2000) Ministers deliberately avoided giving advance directives a statutory basis, but section 4(a) of the Act implies some sort of legislative standing for advance directives. In England no such legislation has yet been placed before parliament. The legislative relationships in terms of advance directives can be viewed below in diagrammatic form.

¹⁷ The Medical Treatment Contract 1995

Current Legal Status of Advance Directives

Statute	Common Law	
Netherlands	Scotland	England

3.1 Legal status of advance directives

In considering selection of doctors for interview, the clinical areas chosen were geriatric medicine, neurology, and oncology. While there are few areas of medicine that do not have the potential to encounter patients with advance directives (paediatrics is the most obvious), these three areas potentially encompass a large variety of patients who have life-threatening conditions and who may have made anticipatory decisions about their medical treatment.

The areas of law thought most likely to have associations with drafting advance directives or, more generally, with medical decision-making are wills and probate and medical negligence. It was decided to concentrate on lawyers working in these areas when approaching firms, but not to the exclusion of other potential areas of expertise.

Interviews with 10 respondents in the areas of law and medicine in each of the three countries were planned to be approximately one hour in length. They were conducted at the interviewee’s place of employment and were tape-recorded in all but four instances. The dynamic aspect of qualitative research meant that flexibility within this research design was able to accommodate difficulties in accessing respondents, and differences in medical and legal categories in different jurisdictions.

The following two tables detail the anticipated and the actual composition and number of interviewees in each of the three countries.

3.2 Proposed interviewees

INTERVIEWEE	NETHERLANDS	SCOTLAND	ENGLAND
<i>Doctors</i>	3 oncologists 3 neurologists 3 geriatricians + 1 other of above	3 oncologists 3 neurologists 3 geriatricians + 1 other of above	3 oncologists 3 neurologists 3 geriatricians + 1 other of above
<i>Lawyers</i>	5 wills & probate 5 medical negligence	5 wills & probate 5 medical negligence	5 wills & probate 5 medical negligence

3.3 Actual interviewees

INTERVIEWEE	NETHERLANDS	SCOTLAND	ENGLAND
<i>Doctors</i> ¹⁸	4 GPs 4 nursing home physicians 1 geriatrician 1 surgeon	4 oncologists 3 neurologists 2 geriatricians 1 GP	4 oncologists/palliative care physicians 2 neurologists 2 geriatricians 1 gynaecology 1 general medicine
<i>Lawyers</i>	4 civil lawyers 6 health lawyers	8 general legal practice (includes both wills and medical negligence) 1 solicitor specialising in incapacity law 1 QC specialising in medical negligence	1 wills & probate 7 wills & medical negligence 1 medical negligence 1 medical law
<i>Other</i>	1 user of advance directives	1 user of advance directives	

Anticipated and Actual Problems

Marshall and Rossman (1995) describe a form of interviewing which focuses on a particular type of interviewee: elite interviewing. These individuals are considered to be 'the influential, the prominent, and the well-informed people in an organisation or community and are selected for interviews on the basis of their expertise in areas relevant to the research' (*ibid.* 83). This type of interviewing has advantages of

¹⁸ It proved to be difficult to select medical interviewees in the Netherlands in the same categories as those in Scotland and England. This was due both to my lack of practical knowledge of the Dutch healthcare system and to the different structure of medical specialities in the Netherlands.

providing valuable information because of the positions the participants hold within an organisation or profession: doctors, and lawyers fall into this category.

There are two types of *élite* interviewees: those who are specific key players and are instrumental in, for example, forming or amending public policy. This group of *élites* is self-selecting and therefore relatively easy to identify when selecting respondents. The second group consists of the key decision-makers, for example, as in this study, doctors and lawyers. Appropriate respondents within this group of *élites* need to be selected by the researcher. In both types of *élites* gaining access is problematic due to their professional commitments, and time constraints. Mordaunt (2000) describes the technique she used to gain access to inspectors of prisons for research into four government inspectorates through approaching an *élite* group of chief inspectors. She warned:

Although there were clear advantages in choosing such an approach, it was a high-risk strategy since only one attempt could be made. In such circumstances very careful planning was essential (*ibid.* 4).

Heads of department in the medical schools in the leading universities of each country were approached to gain access to doctors within the hospital setting. The initial letters explaining the project needed to be informative about the research and the researcher and ‘set out clearly what access [was] required, so that no surprises [were] sprung at a later stage’ (*ibid.* 5). This also applied to the unsolicited letters sent to solicitors requesting information¹⁹. Regardless of employing the above techniques, access to both doctors and lawyers in all countries proved to be problematic. Many felt that they did not have the expertise or the knowledge to participate in the research, others were simply too busy and could not find sufficient time for the interview. In the latter case, interviews were offered by telephone in a written format. In the event, two doctors and one lawyer in England were interviewed by telephone and two lawyers in Scotland completed a written questionnaire. Across the board, however, both doctors and lawyers appeared to be more willing to participate in interviews when they were assured that interviews would last no longer than 45 minutes and that they had a degree of structure.

¹⁹ Copies of these documents can be found in Appendix B.

Lengthy, unstructured interviews were anathema to the respondents in this research, but paradoxically, once they had agreed to participation, many interviewees were happy to speak at length on the subject, often well over the time limit they may have stipulated initially.

It was necessary to be well informed and well prepared for the interviews - what some researchers have called “studying up” (Pierce, 1995: 95). Like Mordaunt, who found it beneficial to use prior knowledge from her career in public service, I found it useful to use my experience of working within a healthcare team²⁰ to enhance the interview situation. A semi-structured interview format allowed a dialogue between interviewer and interviewee to develop, enabling ‘conversations with a purpose’ (Burgess, 1991: 102) to develop.

A potential problem of the élite interview was that of an interviewee trying to control the interview and take charge. The terms and conditions of the interview needed to be established at the outset with the interviewer retaining the ultimate control:

Once researchers agree to give others a veto power, their intellectual integrity is compromised – even if they are mistaken. Researchers have the right to be mistaken (Eisner, 1991: 175).

Fortunately, in this instance, this dilemma was avoided (albeit sometimes narrowly) by being well-prepared, aware of the prospect of this happening, and not allowing sidetracking by the interviewee. Preparation was to be the keynote feature of the interviews. The warning by Fitz and Halpin (1994) was not to be ignored. In their experience of élite interviewees they found that these interviewees

... set out their case not only in correct, connected English sentences, but in paragraphs as well (*ibid.* 42).

This was indeed the case, even among some of the interviewees whose first language was not English. In addition, Mordaunt’s reminder and that ‘élite interviewees take no prisoners’ (Mordaunt, *supra cit.* 9) was well heeded and appreciated.

²⁰ My background in healthcare consists of 17 years (10 years as a Senior Nurse) experience as a psychiatric nurse working within the NHS.

Ethical Considerations

Applications for ethical approval of research projects carried out in NHS premises in the UK usually require ethical approval from the Research Ethics Sub-Committees. On enquiry to the Medicine/Oncology Ethical Sub-Committee, confirmation was received as this research was deemed to fall into the category of 'audit', for which formal ethical approval was not required. Likewise, formal ethical approval was not required in the Netherlands.

There are also ethical considerations in the conduct of interviews that deal with sensitive and possibly confidential issues. Frankfort-Nachmias and Nachmias (1992) assert that social scientists face a conflict between two rights: 'the right to research and to acquire knowledge and the right of individual research participants to self-determination, privacy, and dignity' (*ibid.* 78). While the latter is indeed a right, the former may be overstated and should be seen more as a privilege as opposed to the right to intrude into ethically sensitive areas. Nevertheless the ethical dilemma of whether to undertake research if it interferes with participants' lives is relevant. There is no absolute right or wrong solution to this problem, but the researcher has an obligation to balance any costs to the participants against any potential benefits of the research. This research did not deal with patients and did not ask for information concerning particular cases; therefore the problems associated with interference were of lesser concern, especially when the prospective participants were in positions of power.

Interviewees have concerns about privacy and confidentiality and doctors and lawyers were concerned about the issue of anonymity. In relation to anonymity, interviewees were made aware that they might be quoted directly, but that every care would be taken to avoid any identification of individuals.

Sites within the three countries took account of the limited financial resources available and the time-constraints associated with completing a PhD. Interviewees in the Netherlands were initially identified through liaison with a contact at major university and teaching hospital. From there, further interviewees were found through a snowballing technique with interviewees recommending names of other

professionals who might be able to contribute either as interviewees or as contacts for other respondents. Because medical specialties in the Netherlands are categorised differently from the UK, the anticipated types of clinicians had to be reconsidered. It seemed to be the case that doctors who had most involvement with persons with advance directives were associated with medicine involving the elderly (both in nursing homes and hospitals) and general practice. These areas of expertise made up the majority of the interviewees with one surgeon included through a chance encounter with a lawyer who asked him to accompany her to her interview. Lawyer respondents were found using similar methods using a snowballing technique and by establishing contacts with lawyers who were both interested in legislation concerning medical treatment and who represented doctors in disciplinary hearings. Lawyers comprised those who specialised in health law, civil law, a member of the *Erste Kamer*²¹ and a lawyer involved in reviewing the changes to the Criminal Code relating to euthanasia. Doctors and lawyers were located across the whole of the Netherlands. In addition, one person, who had personal experience of writing an advance directive, was interviewed. This person's interview data was not used in the final analysis, but it was very informative in gaining an understanding of the motivations behind the use of advance directives and giving a "real life" perspective on the subject.

In Scotland, doctors and lawyers in Edinburgh were interviewed because of the proximity of teaching hospitals to the university and because of easy access to a large number of lawyers within the city. A direct approach was used to identify doctors who could be contacted. Letters were sent to the heads of the relevant University Medical School departments for assistance in contacting consultants in Lothian Health Board. This method was successful in establishing contacts with doctors in the areas of elderly care, neurology and oncology and the anticipated mix was achieved with the addition of one general practitioner. This method was also successful in establishing contacts with some neurologists in Newcastle through the snowballing method of finding interviewees.

²¹ Upper Chamber of the Dutch Parliament

Information on solicitors practising in the areas of wills, probate and trusts, property law, and medical negligence and reparation obtained from the Law Society in Scotland was used to identify solicitors who could be approached. These areas of law were chosen because of the greater likelihood of solicitors who had drawn up advance directives or acted for clients in cases concerning medical decisions. Initially solicitors were contacted by letter or email and given a brief explanation of the research. Initially, many lawyers were reluctant to agree to take part in the research citing to lack of time or knowledge of the subject, and consequently the research strategy was modified so that the initial approach letter included the interview schedule in order that the potential respondents were prepared. This was more successful yielding 10 respondents including a Queen's Counsel who specialised in medical law and a solicitor whose area of expertise was the law surrounding incapacity. Eight of those were interviewed in person, two responded by letter; of those interviewed face to face, one did not allow tape recording but did allow note taking.

English doctors and lawyers were mainly based in Newcastle and Tyneside. The city was the site of a large teaching hospital and an accompanying body of law firms specialising in wills, probates and trusts, medical law and medical negligence. Initial contact was made through one Scottish doctor who had contacts in England and this led, through the snowballing method, to several other doctors who were willing to take part in this research. Many doctors were interested in advance directives and were happy to be interviewed; this was especially so with doctors who specialised in palliative care and oncology. In fact, doctors in England were more amenable to taking part in this research than their Scottish counterparts. Most doctors were interviewed face to face, except for two who were interviewed by telephone due to time constraints. All were happy to be tape recorded, unfortunately one tape was corrupted and failed to produce any data from transcription. In this case the data from the interview could not be used for verbatim quotations but the general impressions and any information noted from the interview was drawn upon in the findings discussed in Chapter Seven.

A similar technique to the one used in Scotland was used to identify English lawyers. A list of lawyers currently practising in England, their locations, and their areas of expertise is available from the Law Society in both paper and electronic versions. This was used to identify lawyers who could be approached. They were contacted by letter, email or in person and given an interview schedule prior to the actual interview. This was found to be the most successful method of finding respondents. As in Scotland, it was difficult to find lawyers willing to be interviewed, but all eventual respondents were interviewed face to face, except one where the interview was conducted telephone. All allowed tape recording.

The snowballing technique of sampling used in all three cases works, in the strictest sense, on the principle that each person studied is chosen by previous participant, and therefore linkages between people become apparent. In this study the snowball did not accumulate interviewees in such a regular way. Some interviewees would suggest many others who might be possible participants, while others were unable to make any suggestions of possible contacts. Although this was not the only way to find members of the relevant groups, and many lawyers were contacted through the appropriate law societies in the UK, it proved to be an invaluable approach in finding interview respondents in the Netherlands. Likewise, it was a technique used alongside initial contact with the heads of faculty at the two medical schools in the UK cases; it was used more widely for contacting doctors in the Netherlands.

This purposive sampling technique was not intended to be representative as there never was an intention to generalise from the data obtained in this study. The ability to generalise findings to wider groups and circumstances is one of the most common tests of validity for quantitative research and yet is considered to be of little, or even no, importance for many qualitative researchers (Winter, 2000). Maxwell, (1992) notes that sampling, a vital consideration in establishing the validity of a statistical test, is usually purposeful in qualitative research as opposed to random. Qualitative research almost exclusively limits itself to internal generalisations, if indeed it seeks to claim any form of generalisability at all. These factors were taken into consideration in the data analysis process and on the final conclusions drawn.

Data Analysis

Documentary analysis was useful in acquiring background knowledge and in determining the appropriate questions to ask interviewees, but the most important analysis was that of the interviews themselves. A large volume of material was collected and computer software helped speed up its analysis aiding more conceptual and theoretical thinking (Barry, 1998).

Conceptual and empirical analyses occur simultaneously in case study research. Data analysis is an iterative process, in which the researcher moves from the literature to the data and back to the literature again (see Figure 4.2) (Zucker, 2001). All interviews were transcribed and formatted for entry into a QSR NVIVO (formerly NU*DIST) database. The software, designed as a toolkit for coding text documents, was just used to create categories and code the data, and then used to analyse and explore the coded data. Alongside this method of analysis, overall impressions and ideas that occurred during data collection were added; the flexibility of the software allowing field notes to be coded alongside the interview data. They were added to the transcripts of the relevant interviews and used in the final analysis of the data. As a “code-and-retrieve” software package, NVIVO separated the text into segments, attached codes to these segments of text, and then found and displayed all text segments with a given code or some combination of them. Even using the software at this basic level, it was more systematic and thorough than the manual equivalent would have been (Fielding, 1994).

After transcription, interview data were separated by country and then sub-divided into doctors or lawyers. In the case of doctors, the major themes naturally developed from the structure of the research interview, which focused first on treatment decision-making and then on advance directives. In analysing the data on treatment decision-making, six sub-themes emerged; for advance directives, seven sub-themes became apparent. These are set out in Table 3.4 below.

3.4 Doctors: emerging themes

<i>1. TREATMENT DECISION- MAKING</i>

- | |
|--|
| 1.1 <i>Capax</i> patients: how are treatment decisions made? |
| 1.2 <i>Incapax</i> patients: how are treatment decisions made? |
| 1.3 Power: how does it affect decision-making? |
| 1.4 Decision-making models: best interests or substituted judgement? |
| 1.5 Right to refuse treatment: are persons told of their right to do so? |
| 1.6 Conflicts in decision-making: what do they involve? |

<i>2. ADVANCE DIRECTIVES</i>

- | |
|--|
| 2.1 Doctors' definitions of advance directives |
| 2.2 Use of advance directives |
| 2.3 Hospital/Nursing Home admission: are patients asked if they have an advance directive? |
| 2.4 Legality of advance directives: do doctors view them as legally binding? |
| 2.5 Overriding an advance directive: under what conditions does this happen? |
| 2.6 Patient autonomy: do advance directives affect it? |
| 2.7 Conscientious objection to advance directives: is this acceptable? |

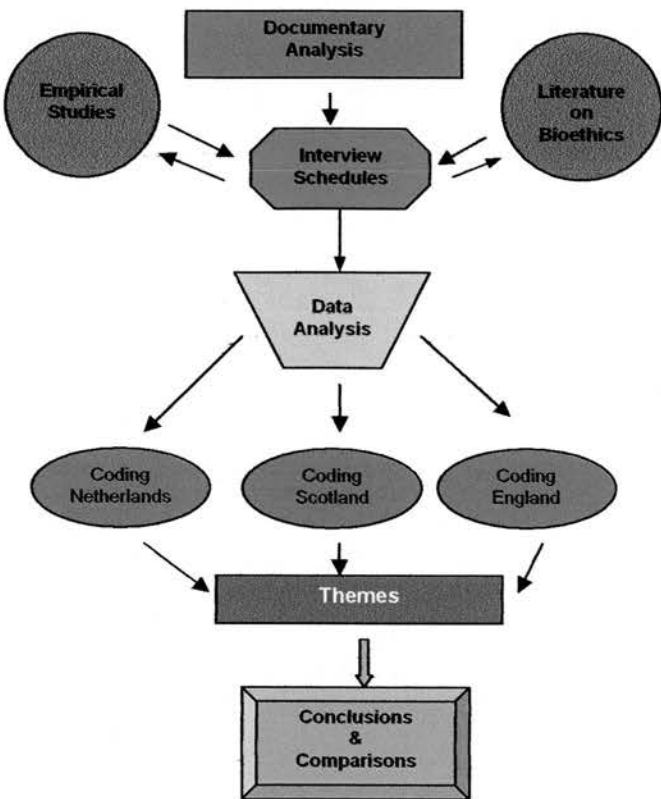
The sections of text in which these themes resided were then coded; in the software, these codes are stored along with the location, or address, of the appropriate passage of text, which specified where the information associated with a certain topic, could be found. The software provides a variety of tools for manipulating the data records, browsing them, coding them, and annotating and gaining access to data records quickly and accurately (Richards, 1999). Although software packages provide a variety of tools and formats for coding, principles are the same as when done manually (Patton, 2002). The themes and sub-themes which were developed from the interviews with lawyers are set out in Table 3.5 below.

3.5 Lawyers: emerging themes

1. LEGISLATION
1.1 Background to legislation surrounding medical decision-making
1.2 Type of law involved in medical decision-making
1.3 Case law on medical decision-making
1.4 Court involvement in medical decision-making
1.5 Capax patients: medical decision-making, lawyers' views
1.6 Incapax patients: medical decision-making, lawyers' views
1.7 Refusal of treatment: legal rights
2. ADVANCE DIRECTIVES
2.1 Legal status of advance directives
2.2 Conflicts in medical decision-making: lawyers' involvement
2.3 Overriding advance directives: legal background

These themes are shown in more detail in Appendix C.

The Data Analysis Process



3.2 The data analysis process

Triangulation – i.e. the use of multiple methods and the obtaining of relevant information from several informants – proved to be a useful tool. It provided a means of testing one source of information against other sources; correspondences and discrepancies were both of value and enabled interview data to be tested against the documentary evidence. Robson (1993) states that this method of testing a hypothesis means that if two sources give the same information then they cross-validate each other. If there is a discrepancy, investigation may help in explanation (*ibid.* 383).

Triangulation was a useful method for validating information and improving the accuracy of findings. Because conceptual and empirical analyses occur simultaneously, analysis of the data is only part of free-flowing guide to forming conclusions from the data. Analysis begins with the literature informing the questions that make up the interview schedules and additional questions were taken from significant topics originating from earlier documentary analysis. The interviews were conducted over a period of months but took into account documentary evidence generated in the previous steps of the process. During the data analysis phase, coding was undertaken by constantly referring back to the documentary evidence in the development of themes (as noted in the above tables). Various key words and issues were grouped into a number of themes and specific trends were identified allowing comparison of like with like where doctors and lawyers from each case/country were compared with each other.

Reflexive Comments on the Methodology

Having completed the data collection and analysis and having answered my research questions, I have had an opportunity to reflect on the methodological choices made for this research and the changes that occurred over the period of this study. Although it initially appeared to be appropriate to collect data, through interviews, from an equal number of lawyers and doctors, this may not have been the best course of action. Lawyers, as stated earlier, tended to respond to many of the interview questions by referring to how the law ought to be rather than to what actually happens in practice. To be fair, this was possibly because litigation in the area of medical decision-making and advance directives is uncommon in all three countries. Lawyers, particularly in Scotland, were reluctant to be interviewed and those who did agree were often interested in the subject from a more theoretical rather than from their clients' perspective. This may explain the responses received. It may have been better to have interviewed fewer lawyers in each of the countries and to have directed the questions towards clarifying the law. Alternatively, postal questionnaires could have been sent out to lawyers asking them to outline their experience of

advance directives with the option of returning to some of them to conduct qualitative interviews in which they could have expanded on their comments. More doctors and fewer lawyers might have generated better results.

Due to my inexperience as a researcher it was probably imprudent to tackle the most unfamiliar element of the research first. It might have been better to conduct the Dutch component of the research last when I had gained more experience in interviewing and had more clarity of what I required in the way of data collection, i.e. after conducting 40 interviews in Scotland and England. Unfortunately, this was not possible at the time, as I had to act quickly to take advantage of practical and financial arrangements that happened to be in place at the beginning of the research project. Additionally, use of more than one city in Scotland and England might have produced a wider range of responses.

Why use the selected methodology?

Reflecting on the methodology used brings various aspects of it to mind. The socio-legal approach allowed me to say more than would have been the case if I had adopted a black-letter law approach. Although black-letter researchers become experts on the law in their particular area of research, I believe that socio-legal research enabled me to address a wider range of questions and to obtain a better understanding of how the law operates in practice. If I had adopted a black-letter law approach I would only have been able to say what statute and case law stated in relation to advance directives. Because there is very little case law in Scotland and the Netherlands there would have been few definitive interpretations to inform my analysis. I would not have been able to discover what the key players in the field thought about advance directives, decision-making, the law surrounding these areas. Social-legal rather than doctrinal analysis enabled me to these questions.

Although I concede that I could have collected more data through a larger scale survey and that it might have been possible to generalise from this, and I accept that there is a need for research of this kind, I maintain that this was not the project to do this. It was interesting to find out what doctors and lawyers thought about advance

directives, in their own words, with the freedom to explore wider issues when they came up, with the continued security of a semi-structured interview schedule. I also could have combined methods but this was not possible for a PhD – time, financial resources and other constraints made this impracticable.

I think it was sensible to compare advance directives in England, Scotland and the Netherlands: the differences in legal authority for advance directives were interesting and significant and there were few, if any, language problems. The number of respondents was manageable and at the same time sufficient. There were no ethical issues or problems in securing access and the respondents, as key decision-makers, were able to provide interesting answers to my questions which generated rich and abundant data.

Key information was gathered prior to the interviews through an analysis of statute law (legislation), case law, professional codes of practice and a review of the academic and professional literature on advance directives and related topics. This meant that I was as well informed as I could be prior to the interviews. I was also able to draw on my experience in medicine and the law to enable me to converse with interviewees on a more equal level. It also helped to persuade interviewees to speak to me. On the other hand, it was difficult to access some potential interviewees who refused because they did not have time or because they had little experience of advance directives.

On a more practical level, I fell into the novice researcher's trap and generated too much data, much of which I was unable to use. The scope of the interviews and the background literature review were initially too wide. It would have been better to read widely but to narrow the focus of the literature review as the research developed. The main lessons learned regarding data collection were: not to ask questions that are not required by the research; to concentrate on fewer research questions and to investigate them in depth rather than too widely; because finding respondents is always more difficult than anticipated; to be aware of the need to trawl widely; and to recognise that everything takes three times as long as initially estimated.

It would have been informative to interview individuals who had written advance directives and their families in order to obtain their views and experiences, however, since these groups would have been extremely difficult to access, a whole new research methodology would have had to be devised to incorporate this group.

Interviewing other healthcare professionals, in particular nurses, would have provided a check on the answers given by medical practitioners. However, they were not key decision-makers, and their opinions, while interesting, are probably not as important as those of the doctors. The homogeneity of doctors' and lawyers' responses within each country and corroboration by other interviewees made the case for checking the validity of those responses less than pressing.

On reflection, although I acknowledge that many changes could have been made, I am satisfied with the main outcomes of the research methodology as it stands.

Summary

Using an interpretive approach, a multiple case-study, qualitative research methodology was adopted. The cases were three countries in question (the Netherlands, Scotland and England) and qualitative findings were reported from doctors and lawyers. Face-to-face interviews were conducted with 10 doctors and 10 lawyers in each of the countries. A semi-structured interview schedule was constructed using open-ended questions to collect data on medical decision-making and the effects of advance directives on professional and personal autonomy. The transcribed interview data was subsequently refined through coding (generating themes) and, along with documentary material, the findings were analysed and comparisons and conclusions developed.

Chapter Four Analysis of Dutch Data

Introduction and Background

This chapter is divided into two main parts: one dealing with lawyers and the other with doctors. Within each part, there are subsections examining the various themes discovered in the interview data. Subsections one and two examine Dutch lawyers' perspectives on the law surrounding treatment decision-making and advance directives. The sections on the law and procedures are laid out at the beginning of this chapter to serve as a background against which the reader can measure the doctors' comments. Therefore, the following subsections explore doctors' views on treatment decision-making and advance directives in this area. A similar format will be adopted in Chapters Five and Six, which examine the same issues from the Scottish and English perspectives.

All quotations are anonymous and identified by use of a number and two preceding letters: *D* to denote Dutch and *L* to denote lawyer or a second *D* to denote doctor.

This chapter shows that all Dutch lawyers interviewed are aware that advance directives are legally binding on their decisions and from a legal point of view, many were happy with their status in protecting patients' rights. They believe that the law states that medical staff should comply with advance directives unless there is a good reason for overriding them and that doctors can be held accountable for ignoring or overriding directives. While this option is open to families to challenge a doctor's treatment decisions, this seldom happens in the Netherlands, where litigation against medical practitioners is uncommon. Lawyers interviewed also consider the WGBO to be a positive method of protecting patients' rights and autonomy and although the doctors interviewed thought it had been unnecessary to pass a law to protect these rights, lawyers felt it to be useful nonetheless. In particular, they believed that advance directives in the Netherlands are felt by lawyers and doctors interviewed to be a way of strengthening the substituted judgement model of decision-making, and to emphasise or enhance decisions made by a patient's representative.

In the Netherlands, patients who have capacity to make treatment decisions have the right to refuse treatment, whatever the possible outcomes, and this right is not disputed by any of the doctors interviewed; in most situations, doctors are happy to allow those persons to express their will. In situations where the patient no longer has capacity, a proxy often takes the patient's place in decision-making and doctors have various methods of making decisions for the patient's medical treatment, together with the proxy, employing either a best interests or substituted judgement model or sometimes a combination of both.

Dutch law clearly instructs doctors to follow a refusal of treatment in certain circumstances and when contained within a valid, advance directive but some doctors do not believe they legally bound them. Doctors were not aware of the legal status of advance directives and believed that if they were in doubt about the legality of the advance directives then the doctor's view would prevail. Often, because of a patient's medical condition, a directive is the only way to determine the patient's wishes but doctors recognised problems in trying to respect a patient's autonomy while fulfilling their duty of care. This conflict may extend to the point where the doctor can no longer treat the patient and must refer him or her on to another physician.

Lawyers

Ten lawyers were interviewed, who specialised in two broad areas of law: civil law and health law. These are notional categories bringing together similar spheres of law for the purposes of this research. Civil law included wills and probate, disciplinary actions involving physicians, and general legal activities. All four civil lawyers had other roles: one was a civil servant working in the Ministry of Health, one was a university lecturer, one was a Senator in the Dutch Parliament,²² and one was a member of the working committee reviewing the amendment to the Criminal Code

²² The Dutch Parliament is bicameral, with the equivalent chamber of the House of Lords in the UK being the *Eerste Kamer* consisting of 75 Senators whose main tasks are to control the government, and to enact and amend existing legislation to changing circumstances.

which legalised euthanasia. The remaining six lawyers practised health law, which encompassed the law of negligence, medical ethics, and mental health & incapacity law (BOPZ). Two of them were also part-time judges in BOPZ law.

All interviews with lawyers were tape recorded, except one, where instead, brief notes were taken. The interviews pursued two main themes, both on Dutch legislation: in treatment decision-making and concerning advance directives.

Legislation

Background

Statute in the Netherlands governs the law on advance directives. It falls into the category of contract law and has been called a “Special Contract” (Markenstein, 1995) because it has extraordinary rules within the civil code. There are virtually no reported cases relevant to advance directives as court cases in the Netherlands regarding patients’ rights are rare and lawyers seldom become involved in disputes between doctor and patient. In cases where the courts do become involved, the doctors’ opinions are likely to be highly influential.

The current legislation in the Netherlands, the Law on Contracts for Medical Treatment (WGBO), introduced an awareness of patients’ rights into the civil code. Before the Act in 1995, the Dutch Medical Society (KNMG), and patients’ organisations had agreed on a protocol stating how to deal with consent to treatment issues. The Act, which is in fact an amendment to Book 7 of the Civil Code, inserting Part 5, Medical Treatment, gave substance to patients’ rights and established them in statutory law rather than simply being a code of practice regulated only by the medical profession.

The background to this law begins in 1986 when members of parliament and spokespersons on medical issues became interested in the medical ethics sphere. The Liberals and Social Democrat Government (The Purple Coalition) introduced the law following a case of a woman who, after giving birth, lapsed into a coma and

remained in that state for 15 years before the Supreme Court ruled that she should be allowed to die. While the concept of futility was well-established, problems were with stopping artificial hydration and nutrition until the courts held that this, too, was medical treatment and could be stopped if the doctor felt it was futile.

Many Dutch Members of Parliament favoured the view that, if a patient decided that he or she wanted no more treatment, then the doctor should not be able to overrule this decision. They also believed that it should be law to have these wishes followed if they had been written down in advance. These proposals had previously been opposed because written wishes were already recognised through court decisions, and so it was thought to be unnecessary to refer to them in the codified law; a situation similar to that in the UK (*Re C* [1994] 1 All ER 819). The rationale was that if advance directives were made statutory, it might cause a new problem, as people might believe that by putting their requests on paper the doctor would be compelled to follow them without any exceptions, which is not the case (DL09). A Senator, who had previously been active in proposing the amendment to legislation, told how the change was helped by the unusual coalition of political parties in power.

I thought it would it be possible that the Purple Coalition would be willing and I had at least two or three professors of law help me write the amendment. The Secretary for Public Health didn't want to oppose my proposal for a change to the law, but the Minister of Justice did. However, he couldn't get the Social Democrats to change to the other side and so the proposal was accepted (DL05).

Type of Law

In many countries (including the UK and the USA) many rules concerning medical treatment are left to self-regulation, codes of conduct, professional guidelines and, like the Netherlands, decisions of disciplinary courts. In the Netherlands, it was considered useful and even necessary to pass an amendment to the existing Civil Code and other legislation in connection with the incorporation of provisions concerning the contract to provide medical treatment, and therefore provide a clear framework as a basis for patients' rights in treatment decision-making. The preamble to the code states:

Whereas we have considered that it is desirable to clarify and strengthen the legal position of patients while taking into account the responsibility of the care provider to act as a competent care provider, and therefore to incorporate certain provisions concerning medical treatment contracts in the Civil Code (Preamble).

While specific cases cannot be solved in advance through legislation, what could be done was to lay down general guidelines, creating certain rules for healthcare providers and patients (DL07).

It is common that when some kind of contract is used it is specifically provided for in the code; for example there are special provisions on rental and labour contracts. As far as the contract analogy goes, reciprocal rights and duties of patients and doctors are unequal; there are many patients' rights and many duties for the doctor, which may have been based on the assumption that it was necessary to make the parties more equal (DL08). The doctor's obligations are wide (Art. 463), as are the hospital's, which bears joint liability for any failure to comply with the provisions of the treatment contract as if it were a party to the contract (Art. 462), departures from the statutory duties are not allowed.

No limitation or exception can be made in respect of the liability of a care provider or, in the case referred to in article 462, of a hospital (Art. 463).

As a situation where there are parties of unequal power involved (doctors and patients), the legislators tried to improve the situation of the less powerful party, i.e. the patient. The patient's obligations are narrow: to pay the care provider unless he or she receives a salary or another form of payment specified elsewhere (Art. 461) and to provide the doctor with any necessary information:

The patient shall to the best of his knowledge furnish the care provider with the information and co-operation which the latter may reasonably require in order to implement the contract (Art. 452).

Case Law and the Courts

Three years after the initial case that inspired the change in legislation, another case advanced the cause to change legislation.

The whole thing was a court decision, in 1989. A woman tried to commit suicide but did not succeed, she was found unconscious with a note saying, "I want to die, let me die." Someone called the emergency services, and she was rushed into hospital where they had about three minutes left to decide whether to resuscitate. In this instance, they did resuscitate her, but since she had given away her possessions this was reason for her to sue the hospital, as they should not have resuscitated her. The court said first of all, and this is the most important thing, that a written advance directive in which the patient refuses something should be respected, but in certain circumstances the doctor may be in doubt and then he should investigate, query the will of the patient. In this case, there were several reasons not to doubt, but because this was an emergency, there was no time (DL07).

The hospital subsequently appealed the decision, but it was upheld and this became a definitive decision in favour of the binding nature of advance directives.

Litigation involving patient's legal rights is relatively rare in the Netherlands. In disputes between doctors and families, lawyers seldom become involved. A situation where a family wants their relative to have a treatment that the doctor feels is futile would rarely end up in court. One lawyer explained the situation as he saw it in Amsterdam.

[W]here there is a court case you know that there were ten other cases which did not reach court but were disputed and others where there was almost a conflict (DL01).

Of course, lawyers do sometimes get involved with disputes between families and doctors, and these disputes do, on occasion end up in court. However, the courts seem disinclined to challenge the doctor's judgment, a circumstance similarly found in the UK courts. Another lawyer illustrated the point with a recent case.

The doctor said the patient should not be admitted to the Intensive Care unit because medical treatment was futile. The daughter went to court to force the doctor to admit her father, the court followed the doctor and said, "If you say it is senseless, then who are we to say otherwise" (DL04).

The first proxy, the person who is supposed to act if the patient becomes incapacitated, is the legal representative, the curator, but few patients have such a person as this position is quite formal and hardly ever is used. The mentor is much more common and is the person who was authorised by the patient in a written

document when he or she was still capable. As many people become incapacitated without appointing a proxy the law provides for additional proxies. A hierarchical order of relatives exists; the first is the spouse or partner and then the group of parents, children, brothers, and sisters. If there is no one in that group, then there will be no one to consent to or refuse treatment as no other person is mentioned in the Law on Contracts for Medical Treatment (Art 465(3)).

When the doctor feels that the patient needs treatment, but the representative refuses, this may constitute one of the exceptions mentioned in the Act which states:

The care provider must in the course of his duties have regard for the standard of care required of a competent care provider and must act in accordance with the responsibilities ensuing from the standard of professional care required of care providers (Art. 453).

The doctor, therefore, may use the law to override the proxy's wishes if these wishes would not satisfy the doctor's duty of care as 'a competent care provider' (Art. 453). The Act does not define this standard of care and it is likely that the court would have to ask the medical profession for an appropriate definition. Where the doctor is not satisfied that a patient's proxy is acting either in the patient's best interests or within the bounds of the patient's wishes expressed through a living will or other method of determining his or her substituted judgement he can request the court to appoint a mentor. Where a curator is in the first place responsible for the patient's finances, the mentor looks after the health and welfare aspects of the incapacitated person. It is a mentor who would be appointed (at the request of the doctor) if the "family" cannot agree among themselves, or if the doctor does not think they really represent the patient's wishes. Nursing home doctors say this use of mentors is fairly common. In the end, the mentor may be able to help each side come to an acceptable compromise, even if the doctor has to acquiesce to some of the family's wishes (against his or her better judgment) because the alternative is worse for the patient.

Capax Patients

All the lawyers interviewed agreed that even before the Law on Contracts for Medical Treatment, competent persons always had the right to refuse treatment, and

that all treatment usually required the person's informed consent (emergency, life-saving treatment is one of the few exceptions). The majority of lawyers interviewed felt that the public was aware of their rights regarding medical treatment and that they knew what to expect when they visited their GPs or were admitted to hospital. Nevertheless, it is not clear whether they were more aware of their rights because of the Act. One lawyer commented that in her experience the Act was not the reason people were better informed; the reason was that the public was less in awe of the doctor as a powerful professional person and felt more able to ask questions, and even challenge decisions²³.

I wonder if the average patient is aware that there is a Treatment Act. I think that patients are more aware of their position, and they don't see the doctor any more as the authority. It is easier for them to complain when something goes wrong, or in their opinion, went wrong. I don't think it is because of the [Medical Treatment] contract, it's more a kind of development that people have the opinion that they have more rights (DL02).

Physicians are not under any obligation to inform their patients of these statutory rights, the Act is silent on any duty on a healthcare provider to explain formally these rights to the patient, but doctors do have an equivalent obligation as the lawyer above explained.

They don't have to tell the patient[s] about their contractual rights, but the doctor has to give the patient information about the choices he has, whether there is a contract or not. If he doesn't do so he violates his contractual obligations and I think he also risks disciplinary action (DL10).

While there is no real change in the patient's right to consent or refuse treatment, the doctor's, now statutory, duty to inform the patient of all his or her choices of treatment (within what might be expected of a reasonable healthcare provider) seems to establish a definite standard. This may be initially felt to be a step away from self-regulation by the medical profession, but since the profession itself decides 'what might be expected of a reasonable healthcare provider' then it is quite a small step.

²³ This contrasts with comments by a doctor commenting on his elderly patient population later in this chapter.

Incapax Patients

When a patient cannot make any comment on a medical decision because he or she is incapacitated, it possibly falls to the patient's proxy, to consent to or to dispute the treatment decision. In any dispute on treatment decisions, the representative of a patient without capacity may challenge the doctor's decision on behalf of the patient. A problem arises when the representative disagrees with what the doctor thinks is best for the patient. The WGBO (Art. 446), states, since there is a contractual dynamic between doctors and their patients or the patient's representative, either the patient or the representative must give his or her informed consent (Art. 450 para. 3). If the patient's representative has prior knowledge of the patient's wishes, either in writing or otherwise, then

[T]he representative cannot oppose his opinion. The [doctor and representative] need each other and they keep each other in some kind of balance ... That is the reason important decisions are not for a judge to approve because we trust that the doctor knows enough and the representative and doctor keep an eye on each other. There is a small margin in this law for the doctor to say you are the representative, but what you suggest now, I will ignore, because I have to conduct the care of the good doctor, which is a condition of this law, and that gives him some space to ignore the representative (DL08).

Therefore, the doctor must follow the patient's wishes, directed through his or her representative while acting in accordance with a body of professional, medical opinion having '*regard for the standard of care required of a competent care provider*' (Art 453). The above lawyer's view of the physician may be more defensible as this 'standard of care' is likely to be based on the standards of the medical profession as a self-regulating body. The doctor may be able to override the patient's wishes by citing standards of care as an applicable reason.

Refusal of Treatment

Patients' consent is required before the treatment contract is implemented (Art. 450(1)), the corollary of this right is also the right to refuse treatment, and this is mentioned in the Law on Contracts for Medical Treatment at Article 450(3). Lawyers' opinions were therefore canvassed to discover whether they thought that patients should be explicitly informed that they had the right to refuse treatment. Few

lawyers interviewed had any specific thoughts on the more general opinion of the right to refuse treatment; one lawyer reported that some of his clients were uncertain about their course of action when they are informed that they can refuse treatment.

I think they are told that they can refuse it as soon as they start saying "Do I need to say yes to the treatments?" There first has to be some kind of hesitance, and then probably the doctors will say, "Of course, if you don't want it you may refuse" (DL04).

The problem, from the point of view of some of the lawyers interviewed, is focused on the requirement of doctors to explain the treatment choices to their patients (Art. 452). The doctor must tell the patient what he or she intends to do,

The care provider shall inform the patient clearly and, if requested, in writing of the proposed examination and treatment and of developments related to the examination, the treatment and the state of health of the patient (Art 448(1)).

On the other hand, if the doctor is 'guided by what is reasonable for the patient to know' (Art. 448(2)) he or she can restrict the amount of information given to the patient. This may be useful if the doctor suspects that the patient may refuse consent for inappropriate reasons. However, if the doctor ignores the refusal of treatment from the patient, this could constitute unlawful touching, which is a cause for litigation. One firm of lawyers were

asking patients or family members to come forward if doctors did not follow the refusal, and we are going to try to see if we can make a case (DL04).

On the more specific point of whether the patient should be explicitly informed of the right to refuse treatment, only one of the lawyers interviewed was prepared to state that the patient should be informed, but not necessarily in those exact terms.

I would like doctors ... [to] do more explaining the alternatives ... [it is reported that] doctors do respect the autonomy of the patient, but they are very much inclined still to take patients along with them on their way to what they think is in the best interests of the patient and they should do more in explaining the alternatives to the patient (DL07).

The general feeling amongst lawyers interviewed was that Dutch doctors did inform patients of their rights up to a certain point and they would not go as far as saying that doctors ignored patients' rights to refuse treatment.

Advance Directives

Legal status

In the Netherlands, there are two types of directives, negative (a treatment refusal) and positive (where the patient asks for something, e.g. resuscitation). The Law on Contracts for Medical Treatment (WGBO) states that a written treatment refusal from a patient, who cannot give consent to or refuse treatment, must be adhered to by a medical practitioner:

If a patient aged sixteen or over cannot be deemed capable of reasonably assessing his interests in the matter, the care provider and a person as referred to in paragraphs 2 or 3 of article 465 shall comply with the apparent opinion of the patient expressed in writing while he was still capable of the said reasonable assessment of his interests and containing a refusal to grant consent as referred to in the first paragraph. The care provider may deviate from this if he deems that there are good reasons for so doing (Article 450(3)).

All the lawyers interviewed were sure of the legal status of negative advance directives and that they were legally binding on doctors. They were also generally happy with the law as a method of protecting patients' rights in medical treatment issues. One stated,

Basically they [advance directives] should be complied with, but as the Act says, doctors may be justified in not acting upon them, and that means that he or she must have a good reason or they can be held accountable. This puts a certain pressure on the doctor, and the family has a kind of instrument with which to challenge him. This changes the positions of the people involved (DL07).

The care provider can attempt to justify any deviation or overruling of the patient's directive, that justification merely requires that the doctor may deviate from this if 'he deems that there are well-founded reasons for so doing' (Art 450 para 3), which without any guidance on what constitutes 'well-founded reasons', does seem to allow the medical practitioner to fill in the terms. While this imposes a certain pressure on the doctor and it may offer the family a kind of means with which to challenge him or her, but there is still no absolute duty to comply with the living will.

Conflicts

As mentioned earlier, lawyers seldom become involved when conflicts between patients' relatives or proxies and the medical team arise. However, it is interesting to see how conflicts in treatment decision-making are resolved and how patient autonomy is protected where advance directives are involved. One lawyer held the opinion that neither doctor nor representatives have cause to dispute the contents of a valid living will.

[L]egally they have no ground to do so, because the living will is there, and if it is correct, and all the demands are fulfilled, it's firmer than the opinion of the representatives. If there is a problem with the family, it is not a legal problem, it is an emotional problem, I think. Legally, it is quite clear, for me, and it is for the WGBO as well (DL08).

While that appears to be reasonably clear, disputes do arise. Lawyers and doctors, however, do recognise that they are best dealt with at as local a level as possible rather than by resort to the law.

Sometimes you have these problems where there is not a [written] living will, but the patient has said things on several occasions "I don't want them to treat me if or when." If the relatives, mostly the children, differ on what the patient's will is, then it is difficult for the doctor, and he has to make a choice (DL02).

This is a recurrent problem with oral statements of future wishes. Oral directives have a difficult legal status as directives for advance care planning have to be made in writing (Art 450(3)). The WGBO does not mention oral directives and the only other method of expressing one's wishes by appointing a proxy. How seriously oral directives will be taken when treatment decisions are being made is still unclear, as some lawyers would give them similar authority to written directives while others would not consider them valid. While oral statements can be taken seriously, they are too easily open to misuse to overrule all other decisions by the healthcare team; at best, it is likely that they will only be taken into consideration by healthcare providers.

Overriding Advance Directives

Lawyers interviewed asserted that the WGBO allowed doctors to override an advance directive provided they had good reasons for doing so. Examples of good reasons given were that new medical treatments had emerged, the advance directive was very old and had not been updated, or that there were concerns about the patient's mental health when the directive was written. One lawyer said,

If there are new treatments and [the doctor] thinks the patient would have decided in a completely different way if he or she had known of these treatments (DL06).

Possibly this fact alone might not be enough,

When it is very old, there may be other circumstantial evidence which brings the doctor to the conclusion that this cannot be true or this is so uncertain that he cannot be responsible. There is no strict rule that it should not be older than X years (DL07).

Many lawyers (50% of those interviewed) thought that advance directives should not be overridden by doctors or healthcare providers, but lack of litigation in this area means that the courts have had little chance to rule on this.

If the physician thought the patient was depressed when he or she wrote it, then the directive could be at risk of being undermined. One lawyer would recommend that clients have the will 'witnessed by somebody with authority who can diagnose that "This patient was not depressed when they wrote this will"' (DL03).

Dutch lawyers have little experience in these types of disputes. Circumstances may change when there is an increase in written advance directives and their subsequent usage rises.

Patient Autonomy and Balance of Rights

The WGBO was designed to be a means of strengthening patients' rights and redressing the balance of power between doctor and patient. While some doctors did not believe that it was necessary to pass a law, which merely documented what had been happening anyway, both doctors and lawyers felt it to be useful nonetheless.

I think [the WGBO] can avoid a lot of discussion about what the patient actually wanted. It is also something on which the doctors can base their decisions, and a patient has to consider all the possibilities when he writes down what he wants. It is different from the situation where he says to a nurse, a doctor, or a friend "If this happens to me I don't want to be treated" (DL02).

A study evaluating the WGBO has been conducted by Schools of General Practice of various universities who reported to the commissioning agency. The conclusions were that the law is achieving its goal of strengthening the position of the patient. While this is felt to be reasonable, the study also reports that more could still be done in terms of implementation and elaboration of the principles for specific situations. One of the lawyers interviewed commented that the rights and obligations are not yet equal, but it is a reciprocal contract agreement, and the emphasis is on strengthening the position of the patient (DL09).

Dutch lawyers interviewed were generally sympathetic to the idea that living wills could help promote patient autonomy, by extending autonomy into the future when the patient is no longer able to assert their own autonomy. When used in certain settings (AIDS wards were mentioned as an example) they can be very useful. They are used also as a way of extending autonomy beyond treatment decisions, to decide who would be with the person when death was imminent, etc. In these situations, they can be positive.

Without advance directives there may be problems in respecting the autonomy of persons who are incapacitated. They can be used to support substituted judgements, to strengthen decisions made by a patient's representative. There is also the unforeseen situation where the proxy is not available to make these decisions and the living will may be sole indication of the patient's wishes. Finally, rather than the autonomy of the professional and the individual being on a pendulum, one lawyer felt that both could be winners.

I think they are not yet perfect, but they are getting more successful, at least they give the patient the right to tell the doctor, to argue. They strike up a kind of debate between doctor and patient; at least that's what I hope. We

have had accounts from clients where they worked, and where the doctors said they felt it was better not to treat certain patients and they felt supported by the declaration. Sometimes it makes it easier for doctors (DL04).

Patients may need to have more confidence in challenging their doctors' decisions and asserting their autonomy, something that may increase with future generations of patients.

Doctors

Of the ten doctors interviewed, four were in general practice, four in nursing home medicine, one worked in general medicine in a major teaching hospital, and one was a practising surgeon. Of those ten doctors, three also had teaching and research appointments at hospitals in three cities in the Netherlands. Unlike General Practitioners in the UK, GPs in the Netherlands do not continue to care for their patients when they are admitted permanently to nursing homes. Nursing Home Medicine has been an organised medical speciality since 1990 (KNMG, 2004), treating people at the end of their lives, and is therefore a useful specialism to include in a study of advance directives.

All interviews with doctors were tape recorded, except one, where instead, brief notes were taken. The interviews pursued two major themes: treatment decision-making, and opinions concerning advance directives and decision-making.

Treatment Decisions

Capax Patients

First, doctors were asked how medical treatment decisions were made for competent patients in order to establish a basis for comparison with decision-making for those lacking capacity.

General Practice

In general practice medicine, doctors often know their patients well and have long-standing relationships with the families. Several had been family doctors for many

years and literally had been family doctors “from the cradle to the grave”. Normally the patient would make his or her own decisions and give or refuse consent; however, in situations where specialist advice was required, many patients looked to the GP for advice in making treatment decisions.

I think that, in the first place, people are responsible for themselves, for what is happening with their body, and I can only give advice or treatment as a professional. For me, being autonomous, as a patient, is important, and mostly, this works out fine. Of course, there are some patients who want to give their autonomy to the doctor, which makes it difficult if it comes to a life and death situation. I tell them that I can give them my opinion, but still it is their decision (DD07).

Visits to the GP usually increase as the patient gets older, with the majority of care being given towards the end of life. The GPs interviewed noted that, in these situations, patients, while still able to give consent, look more and more to doctors for help in making treatment decisions. When this situation is combined with specialist advice then decision-making becomes more complicated. However, the GPs interviewed would normally encourage the patient to make his or her own decisions, often with help. The patient will often return from a visit with a specialist and tell the GP:

The thing is, the specialist says that, “well maybe I have a 10% chance of living a bit longer and I have to have this awful treatment, what do you think?”. We try not to make the decision for the patient but to counsel, to try to find out what the options are, what the patient’s opinion is what is important for the patient and [then] try to mediate between the patient and the specialist (DD06).

It appears that even when GPs tried to preserve the patient’s decision-making autonomy lack of medical knowledge meant that doctors indeed did know best.

Nursing Home Medicine

Medical staff in nursing homes make qualitative distinctions about the levels of consent some residents are able to make. While day-to-day decision-making are almost taken for granted,

I think that most people can make their own decisions; you have to make the distinction about what kind of decisions they make. Things like here and now,

do they want to eat, do they want to drink or do they want help to the toilet, are simple things which people are able to decide for themselves (DD03).

Decisions that are more serious might require some help, but it is still important to allow the person to express his or her will.

About the future, it is more difficult for people to make decisions, so you have to make a division, I think about what kind of problem they have and the kind of person they are, and make a decision about this problem, so you don't have to say he is not able to make any decisions. (DD03)

General Hospital Medicine

Often, when a patient is admitted to hospital, consent to some treatments can be verbal only, and like hospitals in the UK, do not require written consent. With the progress of electronic file systems in hospitals a reduction in paperwork is becoming commonplace.

Yes, we don't sign consents here, when somebody says okay then you write it all in the computer, we have automatic files, so you write down, "I talked to Mr. or Mrs. and s/he wants the operation" that's how it works (DD09).

Incapax Patients

Doctors were asked how decisions are made for patients who have lost capacity, and for those patients whose capacity is in doubt. They were asked to explain the procedure they adopt in ensuring that appropriate treatment decisions were made for patients who had lost the capacity to give consent or refuse treatment. It was stressed that this category of patients would have had capacity at an earlier time and that they may or may not have made their wishes known to healthcare staff, friends, or relatives.

The WGBO²⁴ in the Netherlands is quite clear that informed consent is mandatory. As soon as the patient becomes incompetent, the proxy, whoever it may be, takes his or her place in decision-making and gives or refuses consent. Theoretically, the circumstances are unchanged by the fact that the patient has lost capacity and the doctor must have consent before he or she can treat and that consent has to come

²⁴ See Chapter One

from either the patient or a proxy. If there is no one else then, someone has to apply for a mentor²⁵.

... the residents living in nursing homes are mostly older women. They first look after their husband, and then he dies, and then they become so weak that they cannot look after themselves, and go into nursing homes. If that person, whose parents are already dead, doesn't have children ... [or] ...brothers or sisters ...it ends up that the mentally incapacitated person has no one to represent them on a legal basis, and then you have to apply for a mentor, we do that quite often (DD05).

As mentioned earlier, the mentor looks out for the *incapax* patient's interests and takes the patient's place in decision-making, particularly in give or refusing consent to treatment.

In general hospital care, the family are routinely consulted to find out the patients' previous wishes. There may be circumstances where these are not known, if this happens then one doctor interviewed would ask what the family's wishes were, and it was understood that the same is likely to happen with his or her colleagues.

If you cannot communicate with patients themselves, you can communicate with their family, and you try to get an idea of what they think the person would have wanted in such a situation. That is something which is very important, that's the way the doctors I know do it. If a person has never given his or her opinion earlier, you do what the family would like, that's the way we do it (DD02).

This might also be the case if a more serious intervention, for example surgery, was thought to be necessary.

If they couldn't give consent, well that's for me to assess and to re-assess of course, and we always try to make our decisions with the patient, however incompetent or incapacitated he may be. But if surgical treatment is necessary, we will discuss the treatment decision with the family or the other representative to see if the family gives consent or not (DD04).

Following the WGBO the proxy or informal representative must consent to or refuse treatment.

²⁵ See section on lawyers and the courts.

General Practice

General Practitioners take a slightly different approach. They may see patients in their own homes in the final stages of a terminal illness and it is likely that decisions will have been made in advance. However, in circumstances where this has not been clarified, the GPs interviewed employed a system of consultation; one had a protocol which was followed thus:

First, the physicians' [opinions], in second place the nursing care staff, and in third place the family. The input of the family is highly important, but the physician works according to medical standards (DD10).

A more detailed explanation of the practicalities of this system was given.

Most of the time you talk to the people who are there, and most of the time there is no legal connection, so there is no official mentor or proxy or anyone who is responsible. What you do is also assess whether these people have the best interests of the patient at heart, and that is an assessment that is not done explicitly, but more or less implicitly. You may see that the family is not interested or the family is highly interested, or the family is emotionally involved. The family must be taken seriously, for two reasons, because they are the family and are involved, and they need to know that physicians have compassion and that they have carried out their job well. [Then] they can live with it if things do not work out positively (DD10).

Nursing Homes

Because of the nature of the reasons for admission to a nursing home, prior notice of the patient's wishes can be determined ahead of time. A pragmatic approach to end-of-life care is apparent in this branch of medicine in the Netherlands.

Usually, after the admission of a new patient into a nursing home, we have an intensive conversation with the patient and his relatives, or with the relatives if the patient is incapacitated, to determine the medical policy, not only for that moment specifically, but also for the future. (DD04).

When a patient does not have capacity, doctors still require consent for treatments. While each of the three medical specialties follows slightly different procedures, the general outcome is the same. The patients are consulted, as far as that is possible, the relatives' and proxies' are also taken into consideration, if all this fails and there is no one to make the decision, then the courts must appoint someone to take that responsibility. How the decision is made is discussed in the next section.

Power

Even when patients have capacity to make their own treatment decisions, there can be an imbalance of power in the doctor-patient relationship. The medical practitioners interviewed noted the impact of this power disparity. One GP felt that some patients had *'trouble telling the specialist "No thank-you"'* (DD06). The inability to express their own wishes may be a precursor to relinquishing their personal autonomy, and the elderly are the group most likely to behave in this way. One doctor, when asked if that was because they thought the doctor knows best, declared, *'Knows best? Knows everything! They have a great confidence [in us]'* (DD07).

The reasons why patients place that importance in the medical profession can be widely varied and sometimes may be based purely on faith in the medical profession. According to some patients, specialists and hospital consultants seem to have been given extraordinary powers over life and death, while the GP may take on the role of patient's advocate, increasing the physician's responsibility to help make the correct decision. One doctor summed up the situation:

The power of being able to save lives is a mystery [to some patients]. The patient goes [to hospital] and has no idea what the specialist can do for them ... it is nearly impossible for the patient to really be there and be a partner in making the decisions. Some patients just say, "Okay here I am, tell me what I should do and where to lie down, whatever?" Other patients try to be a partner in this decision-making and to have GPs to be mediators. People who ask for our mediation are better off because they realise that we are one of the people who can help them get what they want (DD06).

There is a great deal of information available about health care in the Netherlands, and there are many patient organisations informing people of their rights and the possibilities of different treatments for a given disease. Television is an important information source, and there is, of course, the ongoing debate on euthanasia. This does not mean that people are resistant to medical advice, one doctor said,

Most people are rather well informed because they are interested in what goes on in health care, [but] there are also people who think they have to do what the doctor says (DD04).

When the Dutch Government introduced the Law on Contracts for Medical Treatment (WGBO) in 1995, doctors were legally considered to have entered into a contract with the patient regarding medical treatment. The principle behind this law was to balance the rights and duties between doctor and patient. However, the main thinking among the physicians interviewed was that nothing had really changed; all that had happened was that what was already taking place was put into writing, *'in practice nothing has changed, there was no change in policy except that it is now acknowledged by the law'* (DD08).

Many patients in the Netherlands have trouble expressing their treatment wishes and this may be an indication of an attrition of their personal autonomy. The elderly are most affected and still feel that "doctor knows best". Patients still believe that doctors have power over life and death and more information about medical treatment is required. The WGBO tried to equalise the balance between doctor and patient but Dutch doctors felt that the law has not made any significant changes because they think the change had already occurred.

Decision-making Models

Decision-making for incapacitated persons can follow different models. Two decision-making models are examined here: the "best interests" model, a paternalistic type of decision-making, where the person making the decision determines what would be best for the patient, often ignoring what the patient would have chosen if that is different; and a "substituted-judgement" model, which gives more consideration to patient autonomy, in which the decision-maker determines what the person would have chosen. This choice may or may not coincide with the patient's best interests (Brett, 1991).

A problem arises when trying to use substituted judgement, as it is never truly possible to know what another person would do in specific situations. This is particularly difficult when the incapacitated person has left no indication of what he or she wished to happen.

As a GP, if you have known the patient and his partner maybe for 10 or 20 years, know their children, know about their household, know how they normally tend to react to complaints or diseases, then I think it makes it easier to make the right medical decision. So that part of your decision making will surely be that you know this patient and you know that he or she is not the one who always wants the last possibility, but it's not that you think that you know what this patient would do (DD01).

In this case it may be possible to accurately predict the patient's wishes, however, in other situations this might not be possible. Many of the doctors interviewed tried to use a combination of both substituted judgement and best interests, but where one approach was required; there was a difference of opinion about which one that should be. One doctor said, in the absence of the patient's wishes substituted judgement would be used. If this failed, only then would the decision be made purely in the patient's best interest:

In common medical ethics, the first rule is to get consent from the patient, and if not, then to try to reconstruct what the patient would have wished were he competent in the situation, and only if there is no way to reconstruct or to get to know the wishes of the patient, then we go to the best interests standards (DD04).

While another thought that best interests was a surer method of decision-making,

We have a very subtle difference here between knowing what a patient said, trying to figure out what the patient would have said, which is quite something else, and doing what is in the best interests of the patient. I think that Dutch law recognises the first and the third of these three possibilities. The second of these ...infers what the patient might have said ...I think it is very shaky ground, because, this has been shown in several research articles that substituted judgement by proxy is quite often a very limited proxy to what the patient would have decided, it's hardly better than chance (DD05).

Finally, the general physician summed up the dilemma:

Well, the paternalistic approach [best interests] doesn't work, and the autonomy model [substituted judgement] has no legal foundation. The autonomy model means that you have to respect the autonomy of the patient, but that does not necessarily mean that you have to follow the requests of the family, so what you do is you try to find out what the patient would have wanted in the given situation and you try to reconstruct it. For that reconstruction, you need the family, because most of the time you don't have a prior experience of the patient (DD02).

These three opinions are examples of how doctors try, in various ways, to make the correct decision for the patient, whether by trying to put themselves in the patient's shoes, trying to find out what the patient might have wanted through the family, or by making a decision in the patient's best interests. Unfortunately, these differing opinions are also good examples of how confused and confusing this area of medical decision-making is for patients and their families, and probably even for doctors.

There seems to be a certain general agreement among the Dutch doctors interviewed that they tried to employ a consistent method of decision-making - a combination of the two decision-making models. Doctors working in general practice and nursing home medicine who were interviewed felt that the substituted judgement model would be used unless there was no way of determining the patient's wishes and the family needed to help reconstruct them. However, not all opinions concurred, one doctor had little time for either decision-making model but no alternative decision-making style to offer in their place.

The Right to Refuse Treatment

As mentioned earlier, one of the basic principles of personal autonomy is the right to refuse medical treatment regardless of whether this may put the person's health at risk. The right to refuse is only useful if the patient is aware of this right and therefore it was relevant to discover whether patients are reminded of this right when they are admitted to hospital, or a nursing home, or on their first visit to the GP. Answers to these questions were mixed, but the majority of doctors interviewed admitted that it was not something they went out of their way to remind or inform their patients; there were several reasons for this.

Doctors working in hospitals who were interviewed said patients are not told that they could refuse treatment; it is '*not said explicitly to them*' (DD08). There was uncertainty at whether these patients actually knew that they had this right and the explanation given was that

... [this generation] of patients was brought up to behave in a certain way toward the doctor. I guess patients nowadays know that they can say "I don't want this", but I doubt that my patients do ...the new old, they know, people

who are now becoming old, also the people who are now 60, 65 are completely different from the group already 80 or 80 plus (DD02).

Similarly, when a patient is admitted to hospital for surgery or some other treatment they are not told that they can withhold consent to all or some of those procedures because patients ...

... come to a hospital with a certain amount of anxiety and a certain amount of trust that the doctors will do what medicine provides in the case of their disease (DD08).

General practitioners interviewed have fewer reservations about informing their patients of the right to refuse treatment. One GP was able to explain why he thought that some patients felt they could not refuse treatment, especially from a specialist. He believed that most patients realised that they could refuse treatment, but that the problem was twofold,

...sometimes it is not clear that they are in the category that should consider refusing, and when they realise that they are in that category, it's often too late to stop the process ... [and] ... people have the idea that they more or less promised the specialist to undergo a certain treatment or tests, it's like being unfaithful (DD06).

Another GP admitted that a nurse or a doctor would never say explicitly that the patient could refuse but doctors would say, *'this is what I would advise you, but you do not necessarily have to want it, or to follow it. It's up to you to make your own decisions'* (DD10). This is not termed as encouraging a refusal, but in a more positive way, the doctor advises that the patient can choose between doing and not doing something.

Doctors interviewed said that patients being admitted to nursing homes in the Netherlands are not told that they can refuse treatment, nor is the family. One nursing home physician expressed a refusal of treatment by a patient as a type of 'conflict' and stated that,

we don't interact with our patients in contractual terms, or in terms of conflict. If you enter a nursing home and you need a physician who is going to talk to you about what you can refuse or disagree with, that's typical of the type of relationship we don't try to engage in with our patients. It is commonly known that everyone has a right to refuse medical treatment, but if people consent to come to the nursing home, they have consented to the care

offered to them in the nursing home, so that is not the first topic when you meet each other (DD04).

This doctor gives the impression that the patient implies his or her consent by presenting themselves at a medical centre, hospital, or similar establishment, but in law this is not taken to imply that one is giving consent to treatment. In the Netherlands, the law states that

Procedures carried out for the purpose of implementing a treatment contract shall require the consent of the patient (Article 450, para 1).

It might be assumed that to consent to treatment the patient would also be aware that he or she could refuse treatment, but to be confident of this it would be prudent to inform them of this entitlement. Many of the Dutch doctors interviewed, however, stated that they might infer that the (potential) patient does consent to treatment just by consulting the physician. Furthermore, there appears to be a belief that it is not necessary to inform people of their right to refuse treatment, as they are already aware of this right. For example, one doctor stated:

[There is an] implicit understanding, and most people in the Netherlands, especially in the region where I am working, know what their rights are, they don't need to have them explained (DD04).

One approach taken when admitting patients to a nursing home was that it was best to discuss this issue when the time is right. While this might not apply to all patients, this doctor would also reassure patients that if they did refuse treatment, they would not be discharged. It may be that patients are fearful of refusing some treatments because they believe they will be left with no treatment at all and this was given as a reason by this doctor for not telling patients of this right.

[Treatment refusal was not discussed] on a routine basis, but then again, in my opinion, there is such pervasive knowledge that you have the power to define treatment, that you have the right to do that, it would be a bit overdone, if the doctors asked for your consent before they treat you, if they were to reiterate that every time. Of course, when the discussion focuses on whether or not treatment will be chosen, then the doctors will say, "Listen, it is up to you, if you don't want it, it's okay. That does not mean that you will be out of here tomorrow, it only means that we won't do this or that." I think, actually, it is mentioned when it is needed, but not all the time (DD05).

Only one doctor mentioned that there was a routine discussion with patients about consent and refusal issues,

... when someone is admitted to a hospital there is a talk with the patient about what ... we are going to do, we make a treatment plan, and we talk about decisions like whether or not to resuscitate [or to take the patient] to the Intensive or Coronary Care Units. That's all done in the first meeting with the patient (DD04).

This doctor was speaking of admitting patients to a nursing home. She also stated that people appreciated being asked these things at that time, and that while it worried them, they were dealt with sensitively and in a non-paternalistic manner. The doctor believed the reaction to the question was dependent on how it was asked.

There is a lot of information at first, but it is the best time to talk about it because people are ill mostly, and most things occur in the first three days, so when you don't say anything and put the family together at the end of the week, the most critical phase is over already, so we prefer talking about it when they first come in. Sometimes people can't decide then, [and] we say well, talk it over and come to us tomorrow or the day after and just tell us and listen to the results of the investigation (DD04).

Although some doctors do speak to patients about their treatment preferences early in their admission to their care, explicitly informing these patients of their right to refuse treatment was often avoided. Doctors gave a variety of reasons for this, from the paternalistic wish not to upset patients at an already anxious time for them to the assumption that since they already knew of this right, to repeat it would be unnecessary. Additionally, some doctors interviewed had the view that if patients turned up for treatment then it was obvious that they wanted some sort of medical intervention, they were unaware, however, to the fact that while a patient might consent to some treatments, he or she might also refuse others. The important issue of treatment refusal, like decision-making models, is that again it is open to interpretation and clinicians' preferences and regardless of the reasons behind it; there appears no real wish to broach this subject with patients in treatment planning.

Conflicts in Decision-making

Disagreements in deciding on the best treatment for an incapacitated person may arise for several different reasons and between several different parties. The family

may want a treatment for their relative that the doctor thinks is futile, or the doctor may believe that certain procedures are worth trying, while the family want their relative to have only conservative treatment or even that treatment be withdrawn completely. When a doctor states that any further treatment is futile, the family often may find that decision hard to accept, especially as futility is an often-disputed notion and rarely an absolute. Other reasons can be rooted more in family relationships and relatives may disagree with ceasing treatment because personal issues need to be resolved. One doctor gave the following example of how family relationships can influence decisions and how these situations can affect healthcare staff:

This is a very difficult problem, because you as a doctor can say that it is not useful to give an [intravenous] infusion, to treat infections, or to give nutrition by some means. Sometimes the family needs more time. So you have to investigate why the family doesn't agree ... I remember one case, where the son wanted to repair everything that was not good in the past, so his father had to stay alive just for him to [sort out] his relationship. Then, it is very difficult for a doctor to say, I will finish this (DD03).

Sensitivity to circumstances such as this affects everyone involved in the patient's care, because the relationship with the patient involves more than just medical care and can become a holistic relationship with the whole family. This was particularly obvious when speaking to doctors who work in nursing home settings: decisions that are acceptable to the doctor may be very difficult for the family. In one case, the doctor communicated with the family to find out what the problem was and to help work it out,

we tried to come to a compromise to treat for three weeks or a month and to see what happens then, or when another infection comes up, to speak together. So it is not the decision of the doctor, it is the family, because you know the family goes on with the situation after death (DD03).

These are a few examples of how differences of opinion can affect decision-making, and how these differences are resolved may become more important than the actual outcome; fragile relationships may be irreparably damaged through poor communication. The doctors interviewed provided varied and important insights on

this topic. One nursing home physician made the important distinction between patients and their representatives making treatment decisions.

Let's put it this way, to a certain extent you [the patient] are allowed to make stupid decisions, you can do or say irrational things, but your representative cannot. The representative should always be governed by the best interests of the patient, so he can't do anything without taking that into account, and that, of course, is something you negotiate (DD05).

The second thing that the representative must consider is what the patient would have wanted if he or she had been able to make that decision. However, what is interesting in this case is what the doctor says about the quality of the decision being made. The patient with capacity has the right to make any decision, reasonable or not, about his or her medical treatment. The decision can be downright foolhardy and even dangerous to the point of death and no one, not even a court can ignore that. The proxy or representative, on the other hand, must be prepared to give valid and applicable reasons for the decision, and in this doctor's opinion, they would be in the best interests of the patient. It is worth noting at this point that the doctor uses a "best interests" primary criterion and presumably, substituted judgement was not applied either because the patient wishes were not known or perhaps were too difficult to justify, overall.

If both doctor and proxy agree that the best interests of the patient are the primary goal, there may be a disagreement on what each believes these best interests to be. In this interview, the doctor believed that the ultimate decision rested with the physician. This may not be legally the case, but there is not enough information on this particular situation to be sure, for example did the patient leave instructions with a proxy for decisions to be made in certain way, or was there a living will? What is interesting here is, the fact that the doctor is sure that his or her professional autonomy trumps the views of the relatives on what the patient's best interests might be.

It might be that the doctor's perception of what are the best interests of the patient is different from the representative, in that case, they should negotiate, and each retain, I think, some responsibility. The doctor on one hand has to argue to provide treatment or supply other types of care and

always has his own responsibilities, so it is in a small minority of cases that the representative and the doctor do not come together and do not reach a consensus, I think the sentiment of the doctor will prevail, but only in the end. Of course, the doctor has to have very good reasons for doing so, and as a doctor must be accountable for that ...the doctor's will is law. I think in the end, if the conflict cannot be settled in a satisfactory way, and then it's the treatment responsibility of the doctor that wins, but that is only in the end (DD05).

Communication is certainly a valuable tool for all parties involved, likewise being given enough time to make a considered and informed decision. One hospital physician described how she would tackle a difficult situation with a family.

Myself, I think most of the problems emerge because of miscommunication. I think if you are able to tell the family exactly what you want and why you want it and what the situation is with the patient at this moment. If you are able to tell them extensively about these things, most of the time you come to the same conclusion. What you do if you don't come to the same conclusion by, let's say, Monday, you say, "We'll wait and think about the decision, we'll speak to each other on Wednesday again." That's the way you try to get an agreement, you give people time to think about things, with the information you have just given them (DD02).

One GP felt that many conflicts could be resolved through more information. The approach taken is perhaps rather paternalistic, in that while the relatives may disagree with the medical opinion, it is because they do not understand and if things are explained more fully, then they will come round. As long as they have their say, things will work out well.

Often you don't see it as a legal conflict but as a psychological difference of opinion. Your first assignment is to find out why people have these opinions. Often you find out that they have the wrong information, they have no clear sight of the prognosis, of what the effect of or how fruitful it will be, so often there is a lack of information, and people want to be heard (DD10).

The crux of the matter, from the doctor's perspective, is that eventually, the clinician's duty of care appears to take precedence. If the family still do not agree, then, according to one doctor, the only other recourse is court action.

As a physician, you have your responsibility according to medical standards, and that's also what you explain to the family, and you also have to accept that sometimes you don't agree and if you don't agree there is always the option afterwards for legal reparation (DD09).

The doctor may go further and refuse to carry on caring for a patient if the family do not agree with his or her medical opinion or decisions. This is not allowed in the Netherlands as the WGBO is a special contract, which protects patients' rights, and the doctor cannot terminate the contract unless there are good reasons for doing so:

The care provider shall not terminate the treatment contract unless there are cogent reasons for doing so (Article 460).

As the Act does not explain what these 'cogent reasons' may be, this article is open to interpretation by the interested parties. There also is no suggestion of any the alternatives for patients if their doctors do terminate treatment contracts. In one case, a GP wanted to carry on with medical treatment, while the family did not agree and wanted their father to die with no further medical intervention. When asked whether, if things arrive at an impasse where he and the family cannot agree, he would carry on with treatment regardless, he replied:

No, I would propose that they look for another doctor, because I am not the right person and we do not get along (DD07).

This raises issues of patient abandonment and possibly a breach of the treatment contract by the medical practitioner. There is a duty of the doctor, in case law, to ensure continuity of treatment and to assist in transfer of the patient to another doctor.

Sometimes the doctor is happy to allow relatives to make the decisions and to carry them out even if they differ from his or her own. This final remark from a nursing home doctor sums up the diversity of opinion and actions that may be taken in a calm and straightforward manner.

If it's not harmful for the patient, their decision is right, but if we think that it is not good for the patient, then we will do our best to convince the caregiver that it is necessary. I think with decisions like that, if we think a person will not get better by treating and the family does want the treatment, it is the doctor who decides, that's also legal, I think. Pointless medical treatment is not given (DD09).

Family relationships may cause conflicts and Dutch doctors may try to compromise with representative in decision-making, but both of these conflicts can be resolved

through passing on more information and through better communication. The patient may make irrational decisions but the proxy/representative does not have that freedom as the patient's interests are paramount and there needs to be valid and applicable reasons for the decision.

Advance Directives

Definitions

The Dutch doctors who were interviewed were familiar with the concept of advance directives or living wills. Most people obtain their living wills from the Dutch euthanasia society, the NVVE, which supplies a document originally drafted by a lawyer²⁶. The definitions the doctors interviewed gave of advance directives were largely comparable and doctors were eager for patients to put their wishes in writing, but considered that having their signatures witnessed was not necessary. For example, one doctor felt that it did not need to be witnessed, '*but I would require it to be signed and dated*' (DD05). Of course, this doctor was not strictly entitled, by law, to demand that the directive be signed and dated, as the statute does not stipulate that signature, witnesses or even dating the directive are necessary requirements. The Act only states that,

a person ... shall comply with the apparent opinion of the patient expressed in writing while he was still capable of the said reasonable assessment of his interests and containing a refusal to grant consent ... The care provider may deviate from this if he deems that there are good reasons for so doing (Article 450(3)).

As the article states, the 'caregiver may deviate ... there are good reasons for doing so' (*ibid*) The doctor could refuse to comply if he or she was unsure that the document was written by the patient and this would be a good reason to insist on a signature and date. It therefore, would be prudent to have the document signed and dated.

²⁶ See Appendix D for examples of advance directives.

Another doctor also encouraged patients to put their wishes in writing but also to discuss the directive with those involved in their care,

If they are capable, I advise [patients] always to write it down, also to discuss it with their children, to get a consensus and I want them to give it to me and I put it in the file, so I have it if they need to destroy it, or if they need to update it (DD07).

Several physicians interviewed raised the differences between two types of directive, one doctor stated

There is a difference between two types of advance directives; one is what you call the negative living will, the treatment refusal or request not to be resuscitated and the other one is what we call the positive declaration, living will in which the patient asks the doctor to do something, for instance to do resuscitation in case of cardiac arrest. The negative living wills such as the treatment refusal have legal status in the medical contract act because it says that the doctor has, in the case of an incompetent patient, to follow the living will, unless he has very thorough grounds not to do so. The negative living will has a formal status and is binding (DD04).

Normally only a refusal of medical treatment is legally binding on doctors, but since April 2001, patients have also been legally allowed to ask for euthanasia in a living will.

The euthanasia declaration is a type of positive living will that has been given legal status. It says that if a patient is incapacitated, but also in a state of unbearable suffering, and there is a living will in which the patient requests euthanasia, and it is applicable to the actual situation, then the doctor is allowed to follow it. So the living will in that case replaces an oral request (DD08).

The legislation does give recognition to the validity of a written declaration of will regarding euthanasia (the so-called euthanasia declaration). The presence of a written declaration means that the physician can regard such a declaration as being in accordance with the patient's wishes. The declaration has the same status as a specific request for euthanasia. Both an oral and a written request legitimises the physician to accede to the request, however, he or she is not obliged to do so and must take into account the due care requirements mentioned in the Act. The due care requirements must be complied with, regardless of whether it involves a request from a lucid patient or a request from a non-lucid patient with a living will. The Criminal

Code and the Burial and Cremation Act (Termination of Life on Request and Assisted Suicide (Review Procedures) Act is amended to include the following section:

If a patient aged sixteen or over who is no longer capable of expressing his will, but before reaching this state was deemed capable of making a reasonable appraisal of his own interests, has made a written declaration requesting that his life be terminated, the attending physician may comply with this request. The due care criteria referred to in subsection 1 shall apply *mutatis mutandis* (Section 2(2)).

In addition to this positive request for treatment (or otherwise) a patient can make treatment requests in an advance directive. As with the euthanasia request, the doctor need not comply, but the request does satisfy the requirement of informed consent.

Some persons do not give much thought to their own treatment preferences until they find themselves in a serious medical situation. In these circumstances, patients often express their wishes orally to relatives or healthcare staff. Doctors interviewed were reticent to give oral directives as much authority as their written counterparts and one doctor would not consider an oral statement to be valid:

No, I don't think that I can, there is no physical proof, I would advise them if they have these feelings and are still capable of putting down on paper, at that moment, not to wait too long. If this didn't become known until the patient was incapable, then I can always discuss it with their family or relatives, but it is a little bit difficult (DD03).

Other doctors interviewed took a different view, and gave oral statements similar authority to written directives, although some doctors believed they did not have the same status as a written statement of the patient's wishes:

In my opinion, and I have said it since 1993, it's not regulated in the law, but oral statements should have the same priority. I do not see any good reason for not having that, as long as the oral statement is communicated to you and not "I think that he would have said". At that moment, it becomes substituted judgement (DD05).

In this doctor's opinion, oral directives merit some sort of legitimate authority. These two opinions are examples of two ends of a spectrum, while the more widely held view is probably somewhere in-between: oral statements of treatment refusal are

weighed up and each case considered on its own merits, taking notice of the relatives concerns and the patient’s prognosis.

Use of Advance Directives

Despite the fact that advance directives are authorised by statute, it appears that relatively few persons take advantage of using them. An example of the spread of their use is illustrated in Table 4.1.

4.1 Dutch Doctors’ Estimated Experience in Dealing with Patients with Advance Directives

<i>SPECIALTY OF MEDICINE</i>	<i>ESTIMATED NUMBER OF PATIENTS WITH ADVANCE DIRECTIVES²⁷</i>
General Practice	~ 2.5%
Surgical	None
Hospital Medicine	10%
Nursing Home Medicine	30 - 35%

(Source: Interviews with Dutch doctors)

There are many people in the Netherlands who have living wills (the NVVE has around 103,000 members). However, the great majority do not take steps to make an advance directive until there is a diagnosis of a serious illness. As one doctor said, *‘I think many people have the idea that a living will is only for people who have a terminal condition’* (DD06). Age is another factor that predisposes people to making living wills. Many people believe that such a document is unnecessary, as they are too young to need one and one doctor stated,

People who are younger than 60 don’t really think about it, that they are going to die, but I guess that people over that age have many more people around them dying and that makes them think about it more (DD02).

Usually with age comes increasing bouts of ill health and more of the person’s contemporaries becoming ill and dying are factors contributing to more people make living wills.

²⁷ People can, of course, have a living will without giving their doctors a copy, and since there is no live register of advance directives in the Netherlands, it is virtually impossible to estimate the percentage of the population who have made such a document.

When you get older and see people around you are older, and getting sick and dying in a way you wouldn't like to die yourself, that's a reason for people to make a will (DD09).

According to doctors interviewed who practised nursing home medicine, residents of those institutions are a group who are more likely to have taken steps towards expressing their wishes for future medical care (see Table 4.1). They may not all have prepared a written document, but usually some discussion has taken place.

I don't think that among the general population, many people have one, but in nursing homes, the percentage is a bit higher. We have several people, who have not written down their thoughts, but they have thought about it, and they have talked about it with their family. So, some sort of opinion is there (DD05).

Dutch doctors interviewed were keen for patients to use advance directives to express their wishes in writing, but until people get older and more frail there is little incentive to do so.

Hospital Admission

The majority of doctors interviewed would expect patients to be asked whether they had advance directives when they were admitted to hospital, however, where they disagreed was in deciding when the most appropriate time was to ask. Some doctors interviewed stated that admission protocols in some areas of care meant that it was a mandatory question, for others, there was a more considered approach. Unlike the United States, where federal law (Patient Self Determination Act 1990) requires healthcare personnel to ask all Medicare or Medicaid patients whether they have an advance directive on admission to hospital, the Dutch Act does not impose this requirement on healthcare providers. This flexibility allows doctors to determine a suitable time in which to ask each patient, while offering more individualised care, one doctor explained,

In nursing homes, it's my experience that, patients are often asked whether or not they have certain opinions about what they want, but that's probably because they are at the end of their life. It is not so typical of hospitals. In several discussions at medical college it was asked whether it would be desirable to ask such a question for all patients, and the general belief was that it was not necessary to do so, they would rather have policies that allow

you ask these questions when the time is right. For example, when patients are deteriorating rather than do it routinely for elective surgery or whatever. The drawback is that you will miss certain situations, people who suddenly become incapacitated and you will not be able to ask for their opinion (DD05).

The lack of any clear guidance or protocols for doctors on a national level means that it will only be chance if patients are asked about their treatment preferences before they are too ill to discuss them. The other option is for patients to broach themselves with their doctors, something that patients may feel disinclined to do.

Legality

The Dutch Law on Contracts for Medical Treatment (WGBO) establishes in statute, a legal contract between doctor and patient, and the obligation for healthcare workers to follow a patient's written directive. However, some doctors interviewed took quite a different view; they believed that they were not legally bound, and that if they did not want to follow them, they were not compelled to do so by law. One doctor put it bluntly,

No, a patient can put it down on paper that they don't want that treatment, or this operation ... If it then conflicts with my opinion of what the patient needs, then they can find another doctor (DD07).

This doctor was in the minority of those interviewed and many more doctors were sure of the legal status of advance directives. Nevertheless, if in doubt, they believed that the doctor's decision would prevail.

I believe that doctors have to be sure that patients really knew what they are talking about when they map out their life in advance directives. If you are not completely sure, you should not err on the side of death, but you should err on the side of life. I would suggest that doctors who find them effective know what their patients want and that they were serious about it. But you will only find that out if you talk to the family, so this is really a process of communication, not a process of reading advance directives (DD10).

Three out of 10 of the doctors interviewed believed advance directives legally bound them and that they should be followed unless they had good reason to override them. While many of the doctors interviewed were aware of the legal standing of advance directives, up to some point, their responses at interview shows the divergent

professional views of that position. This important theme emphasises the gap between the legal framework and the practical realities of this area of medical law, and this will be expanded upon in Chapter seven in discussion and comparison with responses from doctors in Scotland and England.

Overriding an Advance Directive

The Medical Treatment Act states that a patient's clearly expressed refusal of medical treatment must be followed and the 'care provider may deviate from this if he deems that there are good reasons for so doing' (Art. 450(3)). These 'good reasons' can form the circumstances in which a doctor could override an advance directive, and their interpretation of the law may allow some doctors an escape route, especially since the medical profession self-regulates and sets its own standards.

The law is there to be interpreted and translated into reality. First of all the law says that I am obliged to follow the living will, unless I have thorough grounds not to do so. Second, the law states that as a physician, I am obliged to give the care of a good healthcare professional [Art. 453], which relates to the rules of practice that we as a profession have made together. I can make the law less strong because it [professional procedure] is something we devise as doctors ourselves, is not imposed on us by law, so we can make our own policy on how to deal with living wills in these two ways (DD04).

This doctor confirms the notion that doctors interpret the law and to decide how to deal with living wills.

There may be more pragmatic reasons for physicians to override a treatment refusal. One example was given by a GP, who had many elderly patients in his practice,

A patient with dementia, who is severely ill with pneumonia, has a non-treatment contract. If I follow the non-treatment contract, I can't give him any antibiotics. Some people think that if you don't treat a pneumonia, the patient dies, but that it not true, that is something from the nineteenth century, the old man's friend. ... A pneumonia that can be considered the "old man's friend", is one which is accompanied by very few clinical symptoms: the patient is moderately ill, has only a slight fever, and gets sleepy. The type of pneumonia that when left untreated, you slip away, and if you treat it the patient will still slip away because the machinery is off, the body is off. But in a full-blown pneumonia, in a vital demented patient who is

coughing and has a very high fever, if I don't treat him, he will have an extension of his disease, he will have lost some pulmonary tissue, but he won't die. He will become worse, he will be more ill, it will exhaust him, and after the pneumonia has gone, he will have pulmonary problems. In that case, we do give the patient penicillin and we do that under the policy of palliative care (DD04).

This scenario shows that misguided beliefs and lack of medical knowledge may force the doctor to override the directive in order to 'have regard for the standard of care required of a competent care provider' (Art. 453). He therefore 'must act in accordance with the responsibilities ensuing from the standard of professional care required of care providers' (*ibid*). In these circumstances, the patient's autonomy, as previously expressed wishes, will be overridden with the full backing of statute and probably of the medical profession.

Patient Autonomy

Advance directives may be a reliable method of safeguarding a person's autonomy at a time when the person no longer has the ability to make choices. For example, a patient who had no surviving family may rely on an advance directive to help the doctor find out his or her wishes. If the patient requires a mentor to be appointed by the court to make treatment decisions, an advance directive may play an important role in treatment decision-making. One GP felt that '*if it is clear that this is the will of my patient then I will follow it. That is the reason I pay a lot of attention to the living will*' (DD01).

There may be concerns in protecting the patient's autonomy via the living will. For example, certain medical conditions may alter the patient's autonomy to such an extent that the advance directive may be the only way for the doctor to determine the patient's wishes.

Is it advisory or not? In my opinion, a living will, in the case of a patient in a persistent vegetative state, is more important and has more power, than the case of a demented patient, because you can't talk with the [PVS] patient any more, and it gives you a possibility to stop the machines. That is very clear (DD04).

Furthermore, the question of how important the person's autonomy has become in the face of his or her illness is also relevant.

There are always two problems with advance directives: those [written] too far in advance, and several years later, become effective; the other, do you believe the autonomous self who once said he would not be happy being demented or do you believe the present person who is not competent, but seems to be happy? You can only answer this if you first ask the question "how important do you think autonomy is?", and we tend to think it is very important, so we accept the risks, but in other societies, it's the other way around, it would be stupid to follow the advance directive (DD05).

It might be said that this particular doctor regarded the patient's autonomy as being less important than the doctor's own professional autonomy. However, some doctors interviewed believed patients' autonomy to be equally important as their own, and thus respected as such.

The doctor has the right to do things and refrain from things in his own domain, but as a professional, he should do his job and in the profession of a doctor. It must be quite clear that the patient is not a thing you can bend or you can divide in two or whatever, he is a human being having the same rights as you as a doctor (DD06).

The dilemma seems to be one of trying to respect patient autonomy while following two of the basic tenets of medical bioethics: beneficence and nonmaleficence. The doctor is trapped between respecting a patient's autonomy, which may involve a request to withdraw treatment, and his or her duty of care to benefit the patient (beneficence) and to do no harm (nonmaleficence). The advance directive might be able to help with difficult medical decision-making and whether to allow medical autonomy to overrule the earlier expressed individual autonomy of the patient.

Elderly patients often belong to the "doctor knows best" generation and are not inclined to challenge their doctors' decisions. In other situations, respect for a patient's autonomy may compromise the doctor's duty of care or at least the doctor's concept of his or her duty of care. If a patient requires an operation to save his or her life, but refuses to consent to surgery, a doctor may believe that his or her duty of care is at risk. If the patient is competent then the doctor cannot be held responsible for any harm that comes to the patient, the legal aspect of autonomy being that

patients have the right to refuse medical intervention - a negative declaration of will. The converse being that the doctor may need to prove a patient chose a particular course of action by means of an advance directive. This situation confronts doctors everyday, and is expressed clearly by this GP,

It affects me several times a day in my clinic, because nearly every patient has a mind and an opinion that is not congruent with my point of view. Many patients I see are coughing and have asthma and still go on smoking, nearly everyone consults me is obese etc. Already there is an enormous difference between what I think, from a medical point of view, should be the best action and what people like to do and how they like to live, but my calculation of risks is extremely different from what people themselves decide and want (DD05).

The conflict was also expressed by this doctor,

If the patient refuses your care then you don't have a duty, and therefore there is no conflict. If a patient said, "I don't want to be treated", or "I do want to be treated, but only this and excluding that" then that is okay. Of course, if it was against my principles, then I would have a duty to explain to the patient about the possible outcomes, but if he says "Well, listen doctor, thank-you for all these explanations, and your time, but it's still my decision, my belief, my feeling, and I don't want to do it," then that's it (DD07).

The above doctors' opinions are straightforward, but when the patient is in a more serious condition, the outlook may be less clear. A physician who visited a patient at home with a suspected heart attack told this story.

The patient says "Well, thank-you doctor for coming so quickly, and thank-you for diagnosing a heart attack, and what can you do to relieve the pain? Now please let me stay in the house, because I like that" and you try to explain, that this is impossible because if he stays there this might happen or that might happen. I am afraid that sometimes these patients simply get more and more sick until the moment when one says, "We don't know what to do, and we cannot let this person lie here and die". Then the ambulance is called, and the patient is too sick to say no (DD06).

In these situations, it eventually comes to the point where the patient cannot make the decision for himself, so the doctor has to decide anyway. By respecting the patient's autonomy to make his own decisions, the doctor's perception of his or her duty of care may be affected, because the patient is becoming more ill perhaps because of his

or her autonomy. When this was put to the above doctor, the response was as follows:

No, the problem sometimes is that ill people are just as wise or unwise as people who are not sick, so a person who wants to stay at home sometimes does not see the whole picture of that decision. It is one thing to tell the doctor "I want to stay at home." but it is another to realise what happens. It is not up to me to make this judgement, but in real life, people sometimes do stupid things or do things that affect other people, or force other people into conflicts of conscience. So, as a doctor, sometimes people ask me things and I say "Well, if you ask me to do that or not to do that, you make my situation quite complicated" Making the decision is one thing but implementing the decision is sometimes even more complicated. (DD10)

One doctor was forthright about the circumstances where the doctor and patient opinions clashed and the outcome was,

I would explain the situation, I would give my arguments why I think they should do it, and I would give them the medical arguments. I cannot discuss with them the emotional arguments, they are by themselves ... [So my duty of care could] sometimes become overruled by what the patient wants. But, if I think that they are not capable of making that decision, then it is not a problem. In the case where my duty of care can be compromised, and I feel that I am not doing my job properly, and when that feeling is too strong, that can sometimes mean that I have to advise them that they would be best with another doctor (DD07).

Most other doctors interviewed were able to consolidate their duty of care and respect for patients' autonomy. The following view represents the middle ground.

What doctors have to keep doing is try to take care as much as they can within the framework that is acceptable to the patient, so it should not be that if you refuse to have a coronary bypass graft, for instance, then the doctor says, "Well okay, then I won't give you any medication either." Just because that patient doesn't want to be operated on, doesn't mean that he doesn't want to be treated. So, in one way, there is still a duty of care, but I don't think Dutch doctors would interpret it as a conflict because, a conflict would drive them to overruling the patient (DD05).

Conscientious Objections

Sometimes the only way that the doctor can retain his or her, professional autonomy is to pass the patient on to another physician. Many doctors have objections to advance directives on moral or ethical grounds, or because of religious beliefs;

whatever the reason, there may be a duty for the doctor to pass the patient to a colleague for treatment. The consensus among the doctors interviewed, was that as long as the doctor was prepared to come to an acceptable solution with the patient, a conscientious objection was reasonable.

As a professional, you have your own standards, your own ethics, your own culture and beliefs. But you have to tell the patient or the family of the patient and help him look for another doctor if you have professional or moral difficulties (DD03).

One doctor expressed a different view, believing that physicians should not let their own beliefs influence their treatment of patients, and more importantly, put his autonomy before that of the patient.

I think the doctor has a right to have religious and ethical ideas, and I think the patient has the same rights about his own life, so it is not for the doctor to do something different from what the patient wants. If the doctor has a problem with that, in the ultimate case maybe he should decide to become a lawyer or to sell vegetables. I mean that is his problem, it is absolutely not the problem of the patient, so in my opinion it is unthinkable that the doctor, through his religious background, decides to treat a patient who does not want to be treated. It is crazy (DD06).

The WGBO is not clear on the legislative position of conscientious objection. However, there may be a way out for doctors to pass over the patient for conscientious objections by way of the WGBO.

If it is agreed that actions as referred to in article 1653 are to be carried out by a certain person, the procedures necessary for the implementation of the treatment contract must be performed by that same person, (Art 1653h).

In other words, if a doctor is to carry out a certain procedure, then he or she should do so unless 'where it follows from the contract that he may instruct others to perform them ...' (*ibid*). This may allow a doctor to avoid treating certain patients because of an objection to some part of their care, e.g. objections to withholding treatment.

Conclusions

Within the Netherlands, informed consent from the competent patient is always required; this may be implied, by proxy or through an advance directive. Medical practitioners have a statutory duty to inform patients of the treatment choices available to them but under certain conditions doctors may withhold this information. However, the patient's right to refuse treatment can never be overruled although there is not duty for doctors to inform their patients that they have that right to refuse. Where the patient can no longer consent to or refuse medical treatment, both substituted judgement and best interests models of decision-making are used by doctors in the Netherlands. Family relationships, poor communication with healthcare providers and withholding information from patients all contribute to challenges in this difficult area of decision-making.

Statute (the WGBO) provides statutory authority for advance directives, but doctors interviewed in the Netherlands do not necessarily feel compelled to follow them in making treatment decisions for incompetent patients. Doctors found advance directives useful in making decisions for incompetent patient and they may even be useful in reinforcing a patient's autonomy into incapacity. However, doctors did say that they would override directives if their duty of care is compromised. Ultimately, advance directives, according to the doctors interviewed are useful in decision-making but doctors can get round them if necessary. Directives do not present problems to medical practitioners in relation to their professional autonomy in medical decision-making.

Chapter Five Analysis of Scottish Data

Introduction and Background

This chapter follows a similar format to Chapter Four and is also divided into two main parts: Scottish lawyers and Scottish doctors. As with data collection in the Netherlands, a total of ten lawyers and ten doctors were interviewed in Scotland. Interviews again were qualitative and semi-structured, each was 30-50 minutes in length and analysis was conducted using NVIVO qualitative data analysis software, which was used to examine several major themes. These themes indicate how advance directives and treatment decision-making integrates with the current Scottish legal arrangements.

In this chapter the data illustrates that lawyers interviewed in Scotland, like lawyers in the Netherlands, agreed that communication with patients, their relatives, and the exchange of information between doctor and patient are essential in medical decision-making. While advance directives, regardless of their legal standing, can be useful as a method of communication, problems surrounding them, such as the age of the directive, the state of the author's mind at the time of writing, and the pressures that may be put on the person to complete the directive, may be reflected in how seriously the advance directive is taken and consequently how much individual autonomy is retained by the person in the face of their incapacity.

In Scotland, treatment decisions for patients with capacity are generally made after discussion with the patient and sometimes the family. It is recognised by all interviewed parties, however, that while competent, the patient always has a right to refuse treatment regardless of the consequences. However, this right is not always explained to patients on their admission to hospital for treatment. For patients without capacity, the healthcare team will normally make decisions on their behalf by means of discussion with relatives and among themselves and also by referring to the patient's earlier wishes made known by oral or written advance directives. A combination of decision-making models is used: substituted judgment or best

interests. Conflicts usually are resolved through discussion with all interested parties; however, the doctors interviewed gave the impression that they (erroneously) believed that relatives had rights to give or refuse consent in treatment decision-making.

Neither the doctors nor the lawyers interviewed believe that advance directives have legal status at present in Scotland, but the Adults with Incapacity (Scotland) Act 2000, which promotes patients' wishes in its general principles, might provide some protection for patients' autonomy. The lawyers, who were interviewed, more than doctors, believe that the courts might rule in favour of advance directives becoming binding on doctors in the future.

Specialists in care of the elderly and neurology, who were interviewed, criticised advance directives, whether expressed orally or set out in a document, on the grounds that people may change their mind without updating or informing the correct persons. They also expressed concerns about uncertainties surrounding validity of the directive and ensuring that no undue influenced was involved in its compilation.

According to the Scottish interviewees, the *capax* patient has ultimate decision-making power over medical treatments. However, the *incapax* patient only has protection over his or her autonomy if a welfare attorney speaks on his or her behalf or if he or she makes an advance directive. While the welfare attorney has statutory backing through the Adults with Incapacity (Scotland) Act 2000, advance directives rely on regulation only through Codes of Practice monitored by the professional medical organisations. Patient autonomy is less well protected than professional autonomy and the resultant balance of rights is more heavily weighted on the side of the healthcare professional than the patient.

Lawyers

Ten Scottish lawyers were interviewed, all working in the areas of private client law: reparation and negligence, wills and probate, trusts, estate and asset protection planning. Eight lawyers were solicitors who worked with private clients in or around the Edinburgh, one was currently on secondment to the Scottish Executive, working

on updating mental health legislation, from his usual position as a solicitor for a national voluntary organisation, and one was an advocate specialising in civil litigation, with a particular emphasis on medical negligence, and associated advice.

All lawyers gave permission for the interviews to be tape recorded, except one, where instead, brief notes were taken. Another lawyer was unable to keep an appointment for interview, and so replied instead by email. This was satisfactory as further questions were answered by telephone. The interviews pursued two main themes: Scots legislation on treatment decision-making, and lawyers' opinions concerning advance directives under the current legal arrangements.

Legislation

Background

Over the years it had become increasingly evident to both the healthcare and legal professions that legislation was inadequate to meet the needs of persons who had lost mental capacity and that there was a need to modernise and harmonise legislative provision in this area. The Mental Health (Scotland) Act 1984 contains provisions for a guardianship order. Section 37 allowed a local authority or the nearest relative of a patient with a mental disorder to apply for guardianship for a period of six months, renewable for a further 6 months and thereafter annually. Guardians have 3 specific powers: they can require the patient to live in a specific place, to receive medical treatment, education or training, and gain access to see the patient in his or her own home.

Social workers and care managers had been increasingly presented with the practical, ethical and moral dilemmas involved in taking decisions in respect of the welfare, finances and property of individuals who are unable to look after their own interests due to the effects of incapacity. The guardianship order was one way of making decisions on behalf of persons with mental incapacity, but it was inadequate for persons who had lost capacity to take control of their own affairs for reasons other than mental disorder.

Overall there was no comprehensive legislative framework with which to secure the financial, property and welfare interests of an adult who was incapable of acting or communicating their own informed wishes, nor was there a legislative framework to create welfare directives in advance of incapacity. Informal, quasi-legal arrangements often sat uneasily with social workers, care managers and local authorities who were faced with statutory responsibilities for assessment and care planning for those who were unable to safeguard their own interests. This led to an uncomfortable situation where the inflexibility and narrow focus of the law led to many professionals, relatives and carers operating informal arrangements outwith statutory law, acting in what they perceived to be the best interests of the adult with incapacity. Issues relating to the management of the property, finances and personal welfare of adults lacking the capacity to manage their own affairs were dealt with under a variety of common law appointments, such as curators bonis, tutors dative, tutors at law, powers of attorney and continuing powers of attorney.

In the early 1990s the Scottish Law Commission was charged with drafting two consultation documents, resulting in the Report on Incapable Adults (Scottish Law Commission, 1995). This formed the basis for the Scottish Executive's own discussion paper and Bill in 1999, and the subsequent passage of the Adults with Incapacity (Scotland) Act 2000. The Act is a complex piece of legislation which addresses the protection and management of the finances, property and welfare of adults who lack capacity to do so for themselves. It also sets out the legal mechanisms by which people can make their own arrangements for management of their affairs in the event that they lose the capacity to do so themselves. It introduced a new form of guardianship and was intended to make it easier for adults to arrange their affairs in preparation for the possibility of incapacity and for carers, family and public authorities to intervene in an adult's life following the onset of incapacity. It does not cover incapacity to consent to treatment due to a mental disorder, which is still dealt with under the Mental Health (Scotland) Act 1984, although the 2000 Act does cover health issues for those same patients.

Type of Law

In Scotland, the law relating to advance directives and treatment decision-making is a devolved issue and therefore any statutory changes to legislation have to be passed by the Scottish Parliament to become law. Without any statutory developments, the common law and BMA Codes of Practice regulate treatment decision-making for incapacitated persons. The common law states that a person must consent to medical treatment, including any touching, and medical examinations (*Law Hospital v. Lord Advocate* 1996 SLT 848 *per* Lord President Hope at 852F). A healthcare professional who administers any care without the patient's consent could be liable for criminal or civil assault. These civil or criminal wrongs could be asserted in the courts. The only exception to this is the doctrine of necessity which allows medical practitioners to give emergency, life-saving treatment to patients who cannot consent.

Codes of Practice exist and provide advisory guidelines to healthcare professionals on several issues relevant to treatment decision-making (BMA, 1999). These include withdrawing and withholding medical treatment; use of advance statements; and seeking consent for medical treatments. These codes and guidelines are not law and only give advice on best practice in certain situations. The ultimate problem is still unresolved: if a patient is unable to give or refuse consent to a medical procedure there is no easy way to determine who would be able to so do on the person's behalf. Relatives, including the next of kin, have no right to authorise consent to treatment for their relatives, even though they often assume they do have such a right. Lawyers, in their dealings with patients' relatives, observed that families believe they do have the right to make these decisions.

I think a lot of them are probably led to believe that by the medical profession. I've seen it in the hospital myself with my late father, when they were seeking our consent to do procedures when he was dying, which ... I mean I knew that we didn't have the consent but then it was really ... it's funny, when it's your father, you have a slightly different view about it (SL04).

Though it rarely happened, the courts could become involved in appointing proxy decision-makers, but it is understandable that doctors may allow or encourage

families to make the decisions. Advance directives currently have no statutory authority and no case law had been reported in Scotland²⁸ in this matter, therefore, this route would not ease the way to treatment decision-making for *incapax* patients.

After Devolution, the first major piece of legislation passed by the Scottish Parliament attempted to resolve this problematic situation through the Adults with Incapacity (Scotland) Act 2000. The Act sets out various ways in which intervention in the property, financial affairs or welfare of an adult can be made:

- It allows for the appointment of proxy decision makers, who are continuing attorneys²⁹ and welfare attorneys, withdrawers (persons authorised to have access to the adults funds), managers of care establishments who are authorised to manage residents' finances, financial or welfare guardians and interveners (persons authorised to act under intervention orders);
- It provides general authority for medical practitioners to give medical treatment to adults who are not capable of giving their own informed consent;
- It creates, in limited and defined circumstances, provision to authorise medical, nursing, dental or psychological research involving adults with incapacity; and
- It sets out the functions and duties of statutory organisations under the Act, including the new Office of the Public Guardian, the Mental Welfare Commission for Scotland and local authorities.

The 2000 Act is based on a set of principles (section 1) which must be satisfied before an intervention is made.

Principle 1 – Benefit

Principle 2 – Minimum intervention

Principle 3 – Take account of the adult's wishes

Principle 4 – Consultation with relevant others

Principle 5 – Encourage the adult to exercise his/her skills

Principle 3 (section 1(4) (a)) requires that account must be taken of the present and past wishes and feelings of the adult so far as they can be determined by any means of communication. This may be by human or mechanical aid appropriate to the adult,

²⁸ Although there is no Scottish case law, English decisions are likely to be strongly influential.

²⁹ Section 15 (1) and (2) define a "continuing power of attorney" as a power to manage specified aspects of the person's property or financial affairs that continues to have effect when the person loses the capacity to deal with the matters concerned. The person to whom such powers are given is defined as a "continuing attorney". This creates a distinction between powers of attorney that have effect only when the granter still has capacity, but cannot or does not want to act for some other reason, and those that are intended to continue on incapacity. The AWI Act is only concerned with the latter.

and causes oral or written advance directives to spring to mind as a method of communicating those wishes. These general principles must be followed by the courts, by statutory bodies such as local authorities and by individuals. In particular, subsection (4)(a) emphasises the importance of considering the adult's views, both those known to have been expressed in the past and their current views, regardless of their capacity. The adult should be helped to communicate his or her views.

The Act allows a person to discuss and influence how these powers may be exercised on his/her behalf. While the law does not specifically allow for the granter to make any legally binding advance directive, were [someone] to record [his or] her wishes, they would constitute a very clear statement which would help those proposing to intervene to act upon a core principle of the Act: taking account of the adult's past and present wishes. This would not necessarily mean, however, that these wishes would have to be respected (Scottish Executive, 2002: 77).

Part 2 of the 2000 Act allows a *capax* adult to appoint a person to speak for him or her in financial and property matters – Continuing Attorneys. Welfare Attorneys have powers over personal welfare, and may include authority to consent to or refuse medical treatment on the granter's behalf, but this authority will only commence on the granter's incapacity. Granters have wide scope to grant whatever powers they choose, but these powers are strictly interpreted, and this means that there is no possibility of deducing implied powers and, unless expressly included, they cannot be inferred.

Section 16 defines a “welfare power of attorney”, and describes how a valid welfare power of attorney is created. Previously the legal status of attorneys with powers over welfare matters was unclear and there may possibly have been no legal facility to make treatment decisions on another's behalf in Scotland. This section establishes the right to grant such a power, and establishes various safeguards. A welfare power of attorney has authority to make decisions about the personal welfare of the granter.

Part 5 of the 2000 Act refers to medical treatment and research. In this part, medical practitioners are given a general authority to treat adults where there is a certificate of incapacity in force, subject to certain safeguards and exceptions. At common law the doctrine of necessity already allows doctors to give life-saving treatment to

patients who cannot consent or refuse such treatments, this doctrine remains in place and there would be no need to carry out the processes of Part 5 of the 2000 Act in an emergency. Part 5 would be required for non-emergency treatment where the adult is unable to express his or her treatment wishes. Section 1(6) broadly defines “incapable” as including incapable of acting on, communicating, understanding or retaining decisions because of a mental disorder or physical disability. The basic principle of Part 5 is that, in the absence of consent by an adult patient with incapacity, or any proxy authorised under the Act to consent on his or her behalf, the doctor’s certificate of incapacity in relation to the treatment in question takes the place of the patient’s consent. The general principles (*supra*) of the Act must be applied by the doctor in deciding whether to issue such a certificate.

In determining the wishes and feelings of an adult the medical practitioner must have regard for what can be determined of the person’s history. In this respect it can be seen that the principles interact with each other. What may be considered of benefit to the adult must be determined with regard to what the adult considers or once considered to be of benefit.

While you must take the adult’s views and wishes into account, this does not mean that they necessarily must be followed. This consideration must be subject to analysis of risk to ensure that the pursuit of the wishes of the adult (or others) does not place the adult at unacceptable risk. Unacceptable risk could never be considered to be of benefit to the adult (supra cit., 2002: para 4.4.2).

Under the AWI Act advance directives do not have any statutory backing and therefore doctors are under no obligation to do more than take them into consideration. Ten Scottish lawyers tentatively thought giving advance statements/directives statutory basis would be useful,

Yes, I suppose that would certainly be a help if they were entrenched in statute. I don’t know if that would be too rigid though, some doctors would be against it (SL01).

Another lawyer felt that legislation would deal with the problem of vagueness that surrounds the legal nature of advance directives,

Yeah, because that would solve the grey area problem ... it would have to be statutory or some sort of regulation introduced under the Adults with Capacity Act (SL10).

Other lawyers interviewed did not believe that it was necessary to go as far as enshrining advance directives in statute and this lawyer believes that professional regulation is sufficient.

I do not favour a legislative framework and would suggest that a code of practice jointly promulgated by the BMA and the Law Societies of the respective constituent jurisdictions within the United Kingdom is preferable (SL06).

Case Law and the Courts

Prior to the 2000 Act there was very little legislation but there was also very little case law in Scotland. This might be said to be indicative of a kind of paternalistic assumption that, for people who were deemed *incapax*, the treatment would just be given and no questions would be asked about its legal basis. One lawyer recalled such an instance,

I remember a case where a disabled patient had had their teeth removed by doctors and dental staff [with consent of] the carer [who] wasn't actually a blood relative. I felt very much that that shouldn't have happened and other strategies should have been employed but by that time it's really too late to kind of do anything about it (SL07).

The unusual, and possibly only, Scottish case that has been reported in this area was an application to withdraw life-sustaining treatment where the patient was in a stable and persistent vegetative state – the circumstances that gave rise to *Law Hospital NHS Trust v. Lord Advocate* 1996 SLT 848 (see Chapter 1). This case was the first to lay down some sort of guidelines for treatment decision-making in Scotland. These were:

- A patient with capacity had the right to refuse or consent to medical treatment;
- The patient's consent legitimises a doctor's actions;
- Doctors who act on their patients' instruction require no further authority from the courts; and

- It is not up to the court to decide what may be in the patient's best interests (at 825F).

This ruling was welcomed by lawyers for providing some indication of how the courts would deal with such a situation. However, there are a number of well known drawbacks with the court process,

I certainly find the court process, in a number of cases that I have dealt with, completely cumbersome. There's no quick way of going about it, and you have to follow the same procedures, it takes a long time. I had a case where we were acting on behalf of a mother whose 36-year old incapacitated daughter required to be sterilised. Although [the Law Hospital case] was quite widely reported, it took months to go through the whole system ... so you can't get a quick decision. You can't bypass the normal court rules just because you've got a case that needs a quick decision, and that's what's frustrating about doing it through the court. They don't have any kind of streamlined process that you can go through. You've just got to sit and wait with everybody else (SL01).

Court involvement in patients' rights in Scotland is not widespread. Prior to the 2000 Act coming into force, it could take up to a year to go through the whole process. One lawyer expressed her exasperation with the procedure,

You've got to apply for legal aid and the Legal Aid Board is notoriously difficult. They sometimes don't understand what's going on; they say "why can't you do this in the Sheriff Court?" Well you can only petition the Court of Session. You come across these hurdles the whole time. And then your medical reports have got to be up to date and by the time you have the Legal Aid argument, the medical report's out of date. Then you've got to get a consultant to see them again and you've got to get fresh reports so it's a very cumbersome process (SL01).

The 2000 Act will enable many more decisions to be made at a level more consistent with patients' wishes, and possibly without legal involvement. Previously the only "shortcut" available was for the lawyer to address the court to get an interim order for consent to treatment.

Yes, you can do that, there was a chap who had epilepsy and he did have a brain operation. It wasn't urgent but it was going to make his life better because he wouldn't have as many fits but the problem with that was he was on a waiting list ... I've done it on quite a few occasions and the family just can't believe the kind of hoops they've got to go through to get this. So that's why Part 5 of the Incapacity Act will make a huge difference (SL07).

As far as advance directives are concerned, it was difficult for the lawyers interviewed to comment on how the courts might view them. Responses could only be speculative, but it was interesting to discuss what might have happened if the patient in the *Law Hospital* case had had an advance directive.

I think the courts might have found that persuasive evidence. Yes, I think if it comes to it that there's an advance directive, if you end up in court, the existence of one would certainly be persuasive, I think, on the basis that it's the nearest you're going to get to instructions from the person concerned. Yes, it's just unfortunate there's never been a case in Scotland. I think the courts might find the English cases persuasive ...they wouldn't be bound by them because that's not the way the court system of precedence works. They can be persuaded by arguments in some but they would certainly have to make up their own mind according to the law of Scotland. Having said that, the Human Rights aspect, of course, is cross border so any arguments advanced on that basis, in the English courts, would be binding on Scottish courts (SL08).

No cases have been brought before the Scottish Courts in relation to advance directives. This, alongside the above shortcomings of the court process, appear to be the main reasons why Scottish case law is little help for those seeking legal determination on anticipatory decision-making. In future cases, there may be assistance from the general principles of the 2000 Act, especially the principle stating that account should be taken of

the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication, whether human or by mechanical aid (whether of an interpretative nature or otherwise) appropriate to the adult (Section 1(4) (a)).

This part of the Act might be construed by the courts to refer to advance directives as being a communication of the past wishes and feelings of the adult. If the court holds that this is so, advance directives would be given legal standing in Scots law. This, alongside the highly persuasive nature of English court decisions would strengthen their legality.

Capax Patients

All lawyers interviewed agreed that refusals of treatment from a patient with capacity should always be followed. For many, the example that springs to mind is the refusal of blood products by a Jehovah's Witness patient, who is able to appraise the health team of his or her beliefs.

Incapax Patients

When the patient is not able to express those wishes, problems can arise and lawyers were generally keen to make the decision-making simpler and less of a legal minefield for doctors and families.

There is a role for doctors taking the burden of decision-making off families. Unfortunately sometimes the family are likely to feel that it's them that is, as it were, pulling the plug or stopping treatment or whatever. I think sometimes doctors take that burden on but I think families do have a role in bringing things to the table and bringing a perspective to the table, which ought to be taken into account (SL02).

For this to happen the existence of an advance directive might relieve that burden and in this case if the document lodged with the lawyer,

We would give a copy to the relative who is the contact with the hospital and ask them to take it in to give it to the consultant in charge of the case (SL05).

Most lawyers interviewed hardly ever had to deal with decision-making cases for incapacitated patients, except possibly in the context of interventions under the Mental Health (Scotland) Act 1984,

I find that doctors would predominantly go ahead on the basis of the treatment they wanted to give ... but if they were still worried about it, they'd consult the Central Legal Office of the Health Board. In the legal profession as a whole in Scotland, there's a very limited input prior to Adults with Incapacity [Act] into all these issues around decision-making (SL06).

Sometimes in the past, lawyers would be asked more for advice that the healthcare professional was not "breaking the law", especially as there were movements towards legal change in this area.

When I was with [another firm of solicitors] I would quite often get called on to provide reassurances that treatments could be given and I think it was prior to Adults with Incapacity [Act] coming in, there was an increased awareness of the whole issue around the rights of incapacitated people and that started to throw up this issue about medical consent more and more. And so I did get asked quite a lot of questions and sometimes people asked daft questions about what could or couldn't be done with people, like cutting their nails and all this kind of thing (SL10).

Lawyers may still become involved when there is a dispute. Quite often that dispute is between the family members, usually siblings if it's an older person, as to who is responsible for making decisions on that person's behalf. A lawyer had a case where the GP was concerned by a daughter acquiring power of attorney for his patient. The GP did not feel that his patient was actually incapacitated and a dispute arose as to whether the mother was incapacitated and this required a second medical opinion.

Lawyers may become more involved, at least as advisors, as the use of welfare powers of attorney executed under section 16 of the 2000 Act increases.

I do not think lawyers become involved in the decision making process per se relative to the medical treatment of incapax patients unless perhaps in the situation where a lawyer has been appointed as a continuing welfare attorney. Normally, it is a relative or close friend of the granter who will be appointed in this capacity and not a professional adviser (SL03).

There is a minority of cases in which lawyers are consulted, and may be brought before the courts, due to the complexity of the legal issues arising from them. Additionally, a different problem for decision-making may arise if the person has periods of lucidity as well as incapacity.

You've got to kind of judge it, every time you see the person depending on what kind of state they are in at that particular time. We're usually involved when a conflict arises, if there's a kind of question mark over whether or not the doctors can act or should act in this certain circumstance (SL05).

Finally, one lawyer felt that the law surrounding medical decision-making was not quite as bad as some believed.

I think at the moment it's very much of a grey area or, as some say, a black hole. I say a 'grey area'; I mean emergency care is not an issue. If there's some kind of emergency being done, then the medical professionals tend to

just go ahead and do it but there are issues around consent for procedures for people when they're not able to give their consent and my experience is that the doctors tend to be looking to the next-of-kin to be providing consent or some sort of informed consent on their behalf but there's no legal basis for that, of course (SL10).

The relative non-litigious nature of Scottish society and the new provisions of the Adults with Incapacity (Scotland) Act 2000 have meant there is little need for lawyers to become involved in treatment decision-making unless conflicts arise. Lawyers could only contribute anecdotal evidence of conflicts in medical law.

Refusal of Treatment

As can be seen in the section on Scottish doctors, patients are seldom told that they may refuse treatment for their condition when they are admitted to hospital. Some patients do refuse to consent to treatment personally, through instructions to their relatives, or through leaving an advance directive. Where treatment decisions are disputed, some lawyers thought that the family had, a role on the basis that they knew the person better than the doctor,

... it's obviously important to untangle what the family feel about something from what they feel the person may have felt about something and what's best for that person (SL02).

One lawyer had personal experience of being involved in a dispute where the doctors wanted to perform a treatment that neither the family, nor, to the best of their belief, the patient wanted.

I've only come across one and that was the case of my own father. He was basically dying of cancer, and they wanted to cauterise bleeding ulcers. We allowed them to do it once and then they said "we'll have to go and do it again". We said "no, you're not doing anything else ...". But their argument was "well, he's on a gastro-intestinal ward at the moment, we've got to do this", which was one I hadn't heard before (SL04).

According to this lawyer, the doctors, looked to the family for consent, but not for any input into the medical decisions that were being made,

It was a conjoined decision with my siblings and myself and the medical profession were basically deciding but were taking our consent and ... although I didn't say to my brother and sister, "I don't think they're actually

right in asking for our consent because I don't think we're capable of giving it"...(SL04).

Other lawyers interviewed had advised clients on similar issues, one threw light on how,

the families tend to come to us because we, perhaps, have been acting for the parent for a long number of years and would be coming to us basically as a family lawyer, seeking a view and we tend to try and keep it pretty informal. It really depends rather on what the family want to do. I think the issue that I find most difficult with families is the question of withholding of consent rather than the granting of it because most people will say "yeah, actually, you can't give consent without some form of order from the court." You can say to the doctors that you have no problem about that. If, however, you're talking about a situation where somebody is, perhaps, comatose and the hospital are wanting to put in a shunt or something in to tube feed, then that's a slightly different matter. The discussion within the family has to be "well, what's the medical prognosis anyway?" If he or she is going to die anyway, this is just prolonging the experience. On occasion people may say "Mum always said she didn't want to linger and she'd rather go quickly" sort of thing, so withhold consent. But again, you see there are no real grounds for the next-of-kin to make the decision but again they're led to believe by the hospital particularly that it is their decision (SL05).

What is apparent is that, from the perspective of the lawyers interviewed, many doctors assume that the family may give consent to treatment, while this is not legally the case. This misunderstanding of the legal position is a common theme especially among the medical practitioners interviewed. Various explanations may be suggested: doctors may be aware that the family has no authority to make treatment decisions, unless there is a welfare attorney, but permit them to do so because it allows relatives to be part of the treatment process. Alternatively, doctors may be ignorant of the legal position and wrongly ask relatives to consent to treatment; examples of the doctors' views on this point are discussed later in this chapter.

Advance Directives

There is an increasing awareness of, and interest in, advance directives or living wills. Some lawyers interviewed had experience of drafting living wills and powers of attorney intended to enable the person (or, in the case of a continuing welfare power of attorney containing an advance directive, an attorney appointed by the

individual) to determine what medical treatment he or she will or will not receive if certain circumstances arise after capacity is lost. Lawyers who draw up living wills/advance directives would expect them to be witnessed like testamentary wills and that the doctor in charge of the case should be given a copy when the patient was admitted to hospital. Most lawyers interviewed had relatively few dealings with advance directives. One lawyer commented,

I am rarely consulted to draft a living will and frequently have found that clients giving instructions for continuing welfare powers of attorney do not wish an advance directive incorporated. It may be that those considering making living wills are not sufficiently aware of the complexities surrounding their application and legal status to consider that it is necessary to consult a lawyer. As living will forms are available from other sources there are, undoubtedly, more advance directives in existence than my personal experience would indicate but I do not think they are generally common. I imagine their application is more widespread amongst individuals who are suffering from conditions such as HIV/AIDS and who have definite wishes regarding their future treatment (SL03).

Oral advance statements were thought to carry less weight than the written equivalent.

Although the person may have said "I don't want to linger" or whatever ... it's a difficult one to pin down because people's views change as time goes on and I know that's a view about advance directives. Yes, it's all very well that that's what you felt 5 years ago but perhaps anybody should check that that's the way they still feel (SL09).

Caution with oral statements and the problems associated with them were prevalent with the Scottish lawyers interviewed.

Legal status

Of the ten lawyers interviewed, none believed that advance directives were legally binding on doctors in Scotland; this was regardless of the general principles of the 2000 Act, which requires that healthcare staff have regard to the past and present wishes of the person. Furthermore, there has been no court ruling on advance directives in Scotland, and judges would be required only to view English rulings as persuasive. One lawyer stated '*they are not legally binding on doctors but must be regarded as persuasive authority of the granter's wishes at the time of granting*'

(SL06). Some of the reasons why they are not binding are outlined below. One lawyer thought,

Advance directives are not currently binding. In circumstances where the terms of the advance directive do not cover the actual situation, it is more questionable as to whether or not the advance directive should be followed (SL03).

When the Adults with Incapacity (Scotland) Act 2000 was passed, it was clear that the Scottish Executive decided that advance directives would not be contained in the statute, instead the law continued as a vague status quo. However, one lawyer commented as far as the common law is concerned that,

English case law, which has not been controverted in Scotland, states that a competently made advance statement is potentially as binding as a contemporaneous statement by a competent person. My suspicion, however, would be, just looking at how the cases have worked in England and how judges work up here, that in a hard case, I think the judges would go quite a long way to finding reasons not to apply an advance directive if it really meant, for example, that a 17-year old with an eating disorder was allowed to die and I just don't see it happening. I remember speaking to a sheriff who just said that if it came before them, they wouldn't uphold a suicide motivated advance directive (SL08).

An alternative to legislation would be for the courts to decide whether an advance directive was binding. All the circumstances could be taken into consideration, for example, how the statement was made, who made it and who might be named as the proxy; evidence that it was a genuine statement of the person's wishes; and any possible changes since the statement was made. If this were to be the case one lawyer's feeling was that,

If you're going to respect them at all then you should be prepared to consider oral statements as well. Obviously more weight should be attached to something, which somebody has set down and signed in front of witnesses because you can take it that's a considered statement of somebody's views, but people may often say things, which is what they think at the moment (SL07).

Regardless of whether the directive is legally binding there was a certain feeling amongst lawyers interviewed that, ethically, doctors should be made aware of the document's existence, by the person holding possession.

I think certainly if a GP had an advance directive in his possession and if notice of it were in the hospital notes, then I think they'd be duty bound to take that into account. It may not be the actual final decision but it should certainly help in making the decision. I have had one that's been looked at by a hospital who thought it was very clear and helpful (SL09).

Conflicts

What happens when the family disagrees with a patient's living will, does the lawyer become involved in the dispute? These lawyers interviewed gave explanations,

...it is open to family members to seek legal advice in relation to the advance directive of a relative. As the issue of consent to or refusal of medical treatment is one for the patient, it is questionable that relatives would have locus standi if they wished to raise proceedings to set aside a validly executed living will (SL06).

Lawyers may be consulted, if they are known by relatives or doctors treating an incapax patient to hold an advance directive on behalf of that person, to provide such a document and perhaps to comment on its legal status and formal validity but clinical decisions would in the majority of cases be taken by the doctors concerned after giving due consideration to the facts of the case, the terms of any advance directive or the opinion of any continuing welfare attorney appointed by the incapax (SL05).

I've had one or two people I know who signed them. I've had one or two situations where people's learning disability have made them and I know somebody with a mental illness who made an advance directive, and sometimes one of the issues about it is where it has come from really and often they've been encouraged, I think, to sign it and there is sometimes ... particularly not so much advance directives in the sense of withdrawal of treatment issues but often statements about who they would want to be involved or be consulted, should the person have a psychotic episode, for example (SL02).

Many lawyers interviewed felt it unsatisfactory that advance directives might be binding but that nobody knows until either the courts make a ruling or Parliament legislates on the subject,

...and I think it all comes down to how much you trust doctors I suppose, but I think it's unfortunate people do have a very settled and clear view of what treatments they do or don't want but perhaps they can't be given the reassurance that their wishes will be respected. On the other hand, I think it would be very difficult to frame legislation, not just because there are ... people at one end of the argument who are never going to accept advance

directives and it would be hugely political and controversial. So I think there's the political reality of whether you'd ever get legislation but I think there is also a real genuine difficulty in how you would draft legislation, which actually covers all the angles (SL10).

While there is an dissatisfaction with the vagueness of the law on advance directives by the lawyers interviewed, there remains an underlying acceptance of the status quo since legislation would be difficult to draft and likely to cause the same divisions that were encountered when they were introduced in the consultation to the Adults with Incapacity (Scotland) Act 2000 (Scottish Executive, 1999). The English Mental Capacity Bill incorporates advance directives and the points raised by lawyers in both Scotland and England in relation to the accompanying difficulties will be discussed in Chapter Seven.

Overriding Advance Directives

Where there is a degree of perceived or actual conflict between doctor and patient/family, it has been commented that the focus ought to be on trying to remove that conflict, and having patients and doctors communicate more about future treatment issues.

I think where it's important is, where people have a diagnosis, for example, of cancer or dementia or whatever, I think it would be helpful if, as Millan did for people with mental health problems, we have some framework for saying we're going to talk about what might happen and what you would want to happen and wouldn't want to happen and we give you the opportunity to discuss and explore what you would like or not want to happen. Then record it so that people may feel that it's legally binding, I think the primary issue is people feeling that they've had a chance to put forward a view about what they value and what they don't value and what their wishes are. And the doctors have got some way of taking that into account when they do come to make treatment decisions (SL07).

There may be many legitimate circumstances in which it would be essential for doctors to override a living will, but in cases where no such circumstances existed, lawyers were asked for their opinions on how this should be dealt with.

If advance directives are, however, to have any force, I think recourse ought to be made to the courts prior to overriding a patient's expressed wishes. Clearly, medical necessity may not always permit this and any code of

practice introduced would require guidance as to how a doctor should proceed in such circumstances (SL05).

This would include some type of measure to discourage healthcare professionals from overriding treatment instructions in a valid living will without good reason. In the lawyer's opinion, objection to treating patients with living wills because of their religious or moral beliefs would be a good reason to pass the patient to another doctor, but not to disregard the directive altogether.

I do not think disregarding a validly executed advance directive should be a criminal offence but I think some disciplinary sanction must be taken and perhaps a civil liability should arise depending on the facts. I also think it has to be open to a doctor to conscientiously object to adhering to an advance provided that a substitute practitioner can be appointed to act (SL06).

The Abortion Act 1967 contains a clause dealing with conscientious objections which permits doctors to refuse to participate in terminations of pregnancy. The scope of the Act's conscientious objection clause was clarified in a Department of Health Parliamentary answer in December 1991 (Hansard, 1991: Volume 201, Part II, Column 355) and in a Health Service circular in 1994 (DoH, 1994). This made clear that conscientious objection was only intended to be applied to participation in treatment. In addition, the British Medical Association (BMA, 1997, revised 1999) produced an overview on the law and ethics of abortion, based on a comprehensive review of relevant legal documents.

Advice has been given by the BMA where a doctor has a conscientious objection to an advance directive. The BMA recognises that doctors can object on moral, ethical or religious grounds to advance directives, and advise that management of the patient should then be passed on to a colleague (BMA, 1995: para 13.4, 35). There is also an issue of possible disciplinary action by the GMC or civil liability arising in the courts. All things considered this lawyer seems to take overriding an advance directive seriously.

Patient Autonomy and Balance of Rights

Interestingly, although the lawyers interviewed did not think that advance directives were binding, many did believe that they were useful in promoting personal

autonomy. By enabling a patient to make an anticipatory decision regarding treatment to be refused or received after incapacity has been established, the advance directive does offer a person greater self-determination. According to one lawyer, this safeguard is necessary because of struggles between competing autonomies.

A relatively large number of doctors would not act according to the explicit wishes of the patient. One possible explanation could be the conflict between the doctor's and the patient's autonomy, and also between the doctor's duty of beneficence and the patient's autonomy. Communication with patients, their relatives, and the exchange of information are essential in the promoting of ethical decisions (SL03).

If this communication does not happen it may be because of the changing nature of the society we currently live in, where people are becoming much more litigious, and a number of lawyers commented that ultimately the solution has to come from the government, through legislative change.

There is a problem but there's obviously also a desire to see justice done. Is litigation increasing? Absolutely, and complaints to the GMC are increasing as well. I suppose that's what the worry is for doctors. Advance directives could help in that sense, I think it may need some thought about the drafting of [a law] to take into account any human rights argument but yes, I saw that argument being advanced in the reports (SL01).

The solution may be at Parliament's door and the increasing lack of clarity in the common law for treatment of incapable adults is one of the reasons behind the 2000 Act. One lawyer felt that legislation may have been an attempt to even up an imbalance in power between doctor and patient,

Prior to Adults with Incapacity there really was very little legislation, but there was very little case law and I think that's indicative, I suppose, of the fact that there was really very paternalistic assumption that, for people who were deemed incapax, treatment would just be given and no questions were really asked about the kind of legal basis of that (SL07).

The 2000 Act may be considered an advance in personal autonomy, and the discussion in the consultation to reform of mental health law also proceeded from an autonomy perspective. Arguments have stated that advance directives should be respected; however, there may be some distinction between a contemporaneous competent refusal and a decision made in anticipation of a situation. A lawyer, who

saw advance directives as being beneficial, also understood the problems of foreseeing future events with sufficient precision. He pointed out several reasons for their being at variance with personal autonomy,

The argument is that once a person's incompetent, you've lost the opportunity to try and get them to change their mind, that kind of practical issue. One of the problems you obviously have is the issue of how old is the advance directive? How do you know what happened in between? How do you know what the pressures were on them at the time, what the basis of making the statement was? So I think, evidentially, there is a problem about how much you rely on an advance directive in terms of what might have changed in the person between the making of the advance directive and now? And I think also that there are issues around the wishes of the person while incompetent, particularly the issue around, as it were, the kind of life force of a person who is still wanting to live even though they may have said "I don't want to live in a certain situation" (SL10).

Lawyers who were in favour of legislation thought that advance directives with some legal status may be the way forward. The 2000 Acts shows a desire to increase the clarity of the common law basis for treatment decision-making for vulnerable people. A decline in the paternalistic attitude that existed prior to the Adults with Incapacity (Scotland) Act 2000 was considered a great advance in the protection of the patient's personal autonomy.

Doctors

Scottish doctors interviewed specialised in one of three areas: care of the elderly, neurology (mainly stroke (cerebral vascular accidents)), or oncology (radiotherapy or chemotherapy). Three of the doctors were consultants in care of the elderly; three in neurology (mainly stroke patients) and four were consultants in oncology (chemotherapy and radiotherapy). All were consultants in their speciality, and all were asked the same (or similar) questions in respect of their attitudes towards advance directives and treatment decision-making. All interviews with doctors were tape recorded and transcribed before analysis.

Treatment Decisions

Patients within the above medical categories either had the ability to express their own wishes, or had had the ability to do so in the past. All had had the capacity at some time to consent to, or to refuse treatment.

Capax Patients

As in Chapter Four, doctors were asked how medical treatment decisions were made for competent patients as a baseline in order to compare this with the ways in which they made decisions for those lacking capacity.

Care of the Elderly

Patients of the doctors interviewed were generally encouraged to make their own decisions as far as they were able. The ward round was the initial place where a patient's treatment plan might be discussed, and the consultant in charge would inform the patient about his/her problem and the medical plan of action. One doctor gave the following example of one of his patients:

I have a patient in at the moment who's 93 and has full mental capacity. He has a tumour in his bowel so what we did was discuss [treatment] with him at all stages, "Well, you have this tumour, would you consider surgery as an option?" And he said yes, he wanted the surgeons to assess him. So then the surgeons got scans done and it turned out that he was not eligible for surgery but we told him of the other options [radiotherapy and chemotherapy], and he said "what would they involve?", it was an informed decision all the way, we fully involved him in the decision (SD01).

Relatives, family members, and close friends might also be involved in this decision-making process. Most doctors interviewed said they would keep them informed in order to elicit their help if that become necessary. In one case, a doctor had telephoned an elderly patient's daughter.

I just informed her of what had been going on so that if she was talking to her father and he asked her advice, she was party to knowledge, but obviously not always ... for every form of treatment and every patient, one is not always in a position to do so because of time. Phoning 45 relatives would be too much but in specific cases, yes, I would ask staff to keep relatives informed, so that they may be able to work with me (SD03).

In these cases it appeared that doctors kept relatives informed out of courtesy and also in case the patient (or doctor) needed help in coming to a treatment decision.

Neurology

Patients who are being treated for neurological disorders may have some difficulty in making decisions. In particular patients who have suffered strokes may have neurological and cognitive dysfunctions, however, in situations where those patients are considered to have capacity to make decisions; such decisions would be made in conjunction with the patient.

If the patient can make an informed decision with the information that has been given to them, then any decision to perform any treatment will only be made with their consent (SD04).

Oncology

Patients suffering from cancer, in particular those who are not candidates for surgery may need to make more complex and far-reaching decisions regarding their medical treatment. The consultants interviewed did not perform surgery and were involved only with administering chemotherapy and radiotherapy treatments to patients often in the terminal stages of their illness. Consequently, the physician's position in decision-making was less straightforward.

The way that we, in oncology, come to a decision about treatment, is that the clinicians explain the pros and cons of various approaches, because very often, particularly for palliative therapy, there isn't a clear-cut, curative benefit. What the patient wants may determine what would be the right thing to do and there are balances between benefits and side effects and costs and inconvenience and all of that. The patient's attitude and wishes are a very important part of that equation (SD10).

Another doctor commented on the special relationship often enjoyed by doctor and patient within this speciality, one which rose above the usual problems in joint decision-making.

... you have to try and enter the dialogue in all these areas gradually and the huge advantage of most of the patients I see (that are going to die anyway) is that I've known them for months, sometimes years. The real problem is the people who come in very quickly and they're gone, again, in oncology, that's rare. So my views are mine but I think I'm somewhat protected from the really controversial areas, I'm lucky (SD10).

The doctors interviewed try to determine the patients' wishes through information gathered from relatives and friends. A wide range of information is sought on the patients' wishes but patient autonomy is respected, relatives do not make the decisions but doctors considerately keep them informed. Long-standing relationships develop between doctors and patients in oncology and this helps greatly with treatment decision-making, something that was found in the interviews with Dutch GPs.

Incapax Patients

As with doctors in the Netherlands, Scottish doctors were also asked to explain the procedure they adopted in determining appropriate treatment decisions were made for patients who had lost the capacity to give or refuse consent. In particular, the type of conditions that would apply, and how doctors would determine if someone was not able to make a treatment decision were of interest. Consideration of consent and decision-making abilities were issues raised with many physicians and also benefits of having a treatment compared to the detriments of a refusal were also questions to be resolved. Because of the nature of the different medical specialties involved, decision-making for patients without capacity differs from person to person and specialty to specialty.

Elderly

Within care of the elderly, lack of capacity often may be due to dementia-type illnesses where intellectual and cognitive skills are being progressively destroyed. One doctor interviewed believed that people with dementia could have an input into their decision-making although it may be in a very simplistic way, and that even people who are considered unable to manage their affairs, could have a say in their own treatment. This means that strict rules are of little help in these situations, the solution for this doctor was to talk to the patient.

I generally always ask the patients, even if they're quite demented, if there's a simple choice. For example, if it's a choice of a treatment that might involve some blood tests or one that wouldn't, they can often give me an opinion that

they want the best treatment or they don't want nasty needles or anything like that (SD01).

If the patient does not understand, the next stage taken by another doctor would be to consult with relatives or main carers and get their opinion. This could be helpful in coming to a decision in the circumstances,

...occasionally I have come across patients whose relatives have said "ah, well, she has said in her Will that she does not want intensive care treatment or resuscitation" or "she wants to donate her body to medical science" and that's very useful. If the patient has no next-of-kin that we can contact, under common law, we can treat people as we think best (SD02).

This may give the impression that this doctor believes the next-of-kin have a legal right to be involved and to give consent to their relative's treatment. This is not legally correct, but again the doctors interviewed imply that they either believe this is the case, or they allow relatives this privilege regardless of their legal rights. Seeking consent from patients' nearest relatives or next of kin is still taking place as was found in a recent review of the implementation of Part 5 of the Adults with Incapacity (Scotland) Act 2000. Researchers found that since the introduction of the 2000 Act 'not all practitioners had grasped that next-of-kin consent was no longer required' (Davidson *et al*, 2004: 57). Findings also showed that much significance was made of relatives' wishes - they were both being consulted in accordance with the principles of the 2000 Act³⁰, but that their *consent* was also being sought and obtained (*ibid*, emphasis added).

Physical disease may have caused patients to lose decision-making capabilities to a greater or lesser degree. Another doctor approached the problem in a pragmatic way, arguing that no refusal implied consent:

If it is a form of treatment that's going to do very little harm to a patient, and it will have great benefit, I would go along to the patient and say "I'm just going to start you on a new tablet" and explain the reason and unless they gave a very vocal or obvious facial reaction to no medication or that they were refusing medication by closing their mouth, I would take that as being a form of assent (SD01).

³⁰ Section 1(4) (b) states that account should be taken of the views of the nearest relative and the primary carer of the adult, in so far as it is reasonable and practicable to do so.

This would seem to be close to ignoring the need for consent in the first place and is at best, consent by default. Unless the patient can express his or her refusal in some way that the doctor accepts then consent to whatever treatment is being offered will be implied.

The final alternative given by geriatricians interviewed would be to get a second opinion from another physician or ultimately legal guidance.

There was a woman who wanted to go home but I didn't think she was capable of making that decision. So I asked one of my colleagues to come along, independently, and assess the woman's ability. I've done that as well in the past, about whether we should go ahead with an operation. If there was going to be a legal question to it, I would consult the Trust lawyers as well as to whether I was justified in proceeding with a procedure if I felt it was for the patient's wellbeing (SD01).

Neurology

In situations where patients have lost their ability to make treatment decisions, neurologists have to make a judgement even if the patient's cognitive ability is only mildly impaired. The doctors interviewed stated that there would usually be a discussion between the healthcare team, looking at whether the patient was giving a consistent response to the same question over a period of time. However, one neurologist stated that almost certainly the next-of-kin would also want to be involved, and this doctor felt that ...

... often there seemed to be a general feeling that they want to be involved if they are concerned and if they appreciate the consequences of either giving certain treatments or doing certain things, then I'd say, they want to accept a responsibility of being involved in those decisions (SD04).

The common factor for neurologists interviewed was that each case is dealt with on its own merits, and there cannot be a general rule to follow in every circumstance. One neurologist comprehensively discussed all the possibilities that might be considered, firstly if the decision was to treat the patients,

If the patients are unable to make their own views known, then sometimes I make the decision on my own, using information gleaned from the patient's family or the staff. So I am generally fairly happy to make a decision to

intervene, to feed, to hydrate, to treat an infection and my default is generally, if in doubt, to do so because most patients do have the possibility of getting better and the earlier one treats, the more likely you are to be successful (SD06).

In the event that treatment is not considered the best option, then this doctor would approach the relatives,

If one is deciding not to treat, then I will certainly gather views from the family and if they are able to tell me about a patient's previous view about their willingness or not to live in a disabled state or "as a vegetable" as they often say. If they have made an advance directive, that's a bit more clear-cut, then I take that into account in the decision-making. If I think well, I'm not very happy about intervening here, and then I hear from the family that they're not happy, then maybe the view expressed by the patient that they wouldn't want to be like this, would certainly make me more confident to make that decision (SD06).

And also the healthcare team,

I also try and get the views of the junior doctors and the nursing staff and the other members of the multi-disciplinary team, partly to make sure that they are thinking about these ethical issues. I have to say that usually I find them reticent; they do not like to get involved ... some will occasionally express strong views. Usually my experience is not to treat, they're more idealistic than I would be but I'm not always sure that is well grounded in an understanding of the condition or the likely prognosis (SD06).

The common theme among neurologists interviewed was that relatives would be considered at some point during treatment decision-making. The neurologists interviewed did not explicitly state that families had a major say in decision-making. One neurologist did not consult the relatives or the healthcare team unless the decision concerned stopping treatment. It appears that this doctor was only interested in consulting and being supported by others in making hard decisions.

Oncology

If a patient reached a point where they are no longer able to make a decision about further treatment because of their cancer, then none of the oncologists interviewed believed that there would be a circumstance where further treatment would be appropriate. Consequently, there would be no decision to make; the natural choice

would be to allow the patient to die. One doctor stated that there might be an exception,

It's very rare that someone's become so disabled by their disease whom it would still be appropriate to treat. The exception would be some of the cancers, which are curable. They're rare ... and that could cause that problem, but you may find them. In theory, if you've got someone who's extremely sick from ... the cancers that are curable once they've spread, you could have a patient no longer capable of making decisions because of their illness but could still be cured but clearly you've got relatives [to discuss this with] (SD10).

Another agreed that the patient's relatives, while not in the position of being able to authorise treatment, should be included in the discussions, up to a point.

The vast majority of patients of mine who get to the point where they're no longer capable of making a decision, the cancer has caused that and I can't cure them. So it's therefore very rare that you would be contemplating further anti-cancer treatment in a patient like that because it's unlikely to reverse the situation. What you would do is inform the relatives of where you've got to and that further treatment was inappropriate. Now if the relatives are pushing hard, "oh, but doctor, shouldn't we do this or do that?" If, in our judgement, and I use the plural on purpose because if it's a difficult case, I'm not going to make the decision on my own. You get into discussion with people, these things happen when somebody has become unconscious because they've got brain metastases ... if you can't control the loss of consciousness with simple things like steroids, the chance of any active anti-cancer treatment, could reverse it, is actually tiny and I'm afraid we would take a fairly hard line with relatives that there is no point. You're not going to make the patient any better. You're going to put her through treatment that we don't think is appropriate. I can't imagine a circumstance where there's a real decision to be made, because all the evidence points to no ... (SD08).

While each of the doctors interviewed in these three specialties follows slightly different procedures, the general outcome is the same. The patients are consulted, and their choices followed as far as possible, and the relatives' points of view are also taken into consideration; occasionally the healthcare team will become involved, along with second opinions from other consultants. Some doctors are happy to seek legal advice, others do not, but what is apparent from interviews with Scottish doctors is, that no matter how many other views are taken into account, in their

opinion, the ultimate decision rests with the doctor. How these decisions are made is discussed in the next section.

Power

In the UK, doctors take an oath to do no harm, and likewise respect for patient autonomy means that they should not override a patient's considered wishes, even if that means withholding treatment. However, when these two principles diverge, the doctor may think that his/her duty of care is compromised by doing nothing, even to the extent of being at fault by omission. In this situation whether to override the patient's wishes becomes the dilemma. Resolving this dilemma appears to depend on the implications of refusing the treatment combined with the doctor's judgment of the patient's state of mind. The procedure followed a standard course for doctors interviewed who were caring for the elderly,

First of all discussion with the patient ... to ensure s/he is making an informed decision because if it was a rash decision, it could be being made through fear. So I would generally sit down and talk with the patient first of all and explain the benefits versus the risks of the treatment option that I was taking. If they still said "no", what I would do is check whether they were cognitively intact in making that decision because obviously if a person was confused or paranoid or had any psychiatric psychopathology behind it, they may not be making a rational decision. If I felt that it was a treatment vital to their wellbeing, I might ask one of my psychiatry colleagues to assess the patient independently to see if they were able to make a rational decision themselves and if they weren't, I would ask their advice on what would be the next best option (SD01).

Would the doctor go so far as to say his or her professional autonomy or duty of care can actually override a patient's personal autonomy?

It depends on the state in which the patient is expressing their views, their autonomy. If they have a grasp and an understanding of the full situation in which they are, if they have an understanding of the prognosis, of the possible interventions and then they say no, they don't want them, then I don't think I've got any right to impose those. However, that is uncommon because often patients who refuse interventions are not fully capable of understanding the implications of them. So sometimes, yes, you can make a decision about what's in their best longer-term interests, in which you may have had to override their immediate autonomy (SD06).

Neurologists interviewed stated that the reasons behind the patient's decision were paramount in allowing the decision to stand or be overridden. One neurologist gave the following example.

If somebody said to me "if I have a very severe stroke and I'm going to need nursing home care and I'm not going to be able to look after my own needs and I get a chest infection, I don't want to have antibiotics", I think that is fair enough. If it was somebody who says "oh, if I have a stroke and I can't talk, I've always talked and talking is my life, so I don't want any treatment", I would say "well, as your doctor, I cannot accept that because I don't think that is the right choice." So, unless there was a written legally binding advance directive, I wouldn't go with that, no (SD04).

This doctor implied that the patient's decision might be overridden if the doctor thinks it is the wrong choice. Another neurologist stated,

The problem seems to be in getting the message across about something in the future, which is less easily grasped than something in the present the now, which is when the discomfort is happening. So sometimes, yes, you can make a decision about what's in their best longer-term interests, which you may have had to override their immediate autonomy. For example, a patient may know that he/she does not want a tube inserted, but does not think beyond that to the implications of not being fed, that is, starving to death (SD06).

While there seems to be a degree of paternalism present, and this doctor would be prepared to override the patient's short-term autonomy, there seems to be a notion of respect for patient autonomy as a general principle. Both doctors, however, are clearly using their greater power to overrule patient wishes.

Oncologists interviewed felt, often due to the severity of the condition and the poor prognosis, that there may be less discord between doctor and patient. The oncologists interviewed all stated that they usually had built up a relationship with their patients and they normally would be aware of the reasons behind a patient's refusal to have certain treatments. One gave this hypothetical example based on experience.

Take somebody with a bowel cancer, who said "No, I don't want any surgery. I don't want any treatment for this bowel cancer", and I knew that they had a good chance of making a full recovery, I would usually have a meeting with them and their family, after talking with them and if they were still adamant and they were cognitively intact and were making an informed decision and

they said "I hate ..." , and there is a logical reason for not going through with it, then I would respect their decision (SD10).

Likewise with futile treatments, the oncologists interviewed would seldom go along with giving treatment against their better judgement. Instead, they would explain to the patient that the treatment would be more likely to make them worse rather than better and offer them the option of a second opinion. The oncologists interviewed seem to have a greater respect for patient autonomy than the neurologists and geriatricians interviewed. This may be due to oncologists having a higher percentage of relatively younger patients than the other two specialisms and also have relationships with their patients that have had several months to develop. Of all the specialisms, neurologists interviewed most used their power over patients to overrule patients' wishes.

Decision-making Models

As with doctors in the Netherlands, Scottish doctors were asked about two accepted methods of surrogate decision-making: the best interest test, and substituted judgement. Decision-making by means of what may be in the patient's best interests is often criticised for being too paternalistic towards adults, and more practical when dealing with children and minors (Scottish Executive, 2000: 1) whereas substituted judgement is more in line with the autonomous wishes of the patient (Beauchamp and Childress, 1994: 173). These two types of decision-making and any particular type or combination of methods they used for patients *incapax* patients were discussed with the doctors.

Doctors interviewed who were caring for elderly patients were aware of the dangers of only looking to the relatives for advice on what the patient might have decided. This led to no one particular method of decision-making being used and to an arrangement where many factors were taken into account. One doctor stated,

I would say that I would take the relatives' opinion into account and it would be a ... a combination of what's in the best interest for the patient, what the patient has previously expressed, what staff on the ward or friends of the patient would think. It's a combination. I know that there are nursing homes, where they asked patients who were competent, "what would you like

if such-and-such a scenario came up?" They found that the surrogate decisions made on behalf of the patients, by relatives, often didn't correlate with what the patients themselves wanted (SD01).

In neurologists interviewed, the best interests test was the predominant model, even when that might go against the patient's previously expressed wishes as told to relatives. However, the doctors interviewed were aware that problems might arise in more serious circumstances, and felt that other persons should be involved.

They're saying "look, from what I know of my wife/Mum/etc., I don't think she would want to be suffering like this. If you're telling me that you can control her suffering ..." We've, very rarely, gone through the legal issues because so many of these circumstances are not about cure or non-cure, I've never had a cure or non-cure choice that would incapacitate a patient, that would be difficult. I think under those circumstances, we would probably want to start getting involved with a patient's GP and others because I wouldn't be prepared to say they [the relatives] had the right to say "don't bother doing anything", if I knew that treatment had a reasonable chance of cure (SD05).

For the oncologists interviewed, the patient's wishes would always be taken into consideration, and would carry more weight than relatives expressing what they felt were the patient's wishes. Relatives could be useful, however, if there were questions about a person's wishes,

... [although] if there was a major discrepancy, they might just help to clarify what the patient's view was but I don't think they would help in any other way (SD07).

It would appear, from the oncologists interviewed, that the model of decision-making used was more heavily weighted on the substituted judgement side, although it was not the only consideration. The problems of both methods of decision-making were exemplified by one neurologist,

I think [substituted-judgement] has got major dangers and I suppose in my designing best interests, I take into account quality of life etc., but I don't think I can put myself in their position, nor can any able-bodied person put themselves in that position. I've seen too many patients who have expressed the view, prior to their problem that they wouldn't want to be alive in any state such as with difficulty with language, immobility. But then when they are put into that position, they cling to life and continue to cling to life as they make some partial recovery. That's always the difficulty with families as well.

They, like I, are generally often able-bodied and wouldn't swap a disabled life for it. That doesn't mean a disabled life, once you've got it, is worse than death. And I think they're right, death is pretty final (SD04).

This small number of interviewees shows the problems in using definitive models of decision-making. The most dominant method used by Scottish doctors was to look at what would be in the patient's best interests.

Right to Refuse Treatment

When a patient is admitted to the hospital it is unusual for healthcare workers to mention their right to refuse treatment. When asked if this would that be brought up on admission, doctors caring for the elderly interviewed did not specifically ask the question. One reason was,

It would only be brought up if the patient said, at the very beginning, "I don't want certain treatments." They're always asked about resuscitation, for example, we say it's Trust policy to ask people, "If your heart stopped, would you like to be resuscitated?" That's documented at the beginning of the notes but not with regard to refusing treatment (SD01).

Interviewees in neurology and oncology differed in their practice. One neurologist claimed that it was very much highlighted at the beginning of the admission procedure, and patients were told that it was an option to do nothing. Conversely, another neurologist felt that it depended on the treatment offered,

Mostly we rely on implied consent, i.e. they do not say "no" and they go ahead and that covers most things in terms of giving normal nursing care and administering drugs. I think we are patchy in talking to patients about the purpose of particular interventions and, indeed, I don't think the Health Service could work if we went into the details of all that. Obviously we are rather better at discussing the more invasive investigations and treatments. Anything that I think is potentially uncomfortable, I would discuss with them and say "this is why we're doing it, are you happy?" So I would give them the opportunity to say, no, they're not. Sometimes we don't investigate people, we would like to but they prefer not to. We don't treat them because they don't want to [be treated] (SD06).

The issue of implied consent is very dangerous for doctors as informed consent is required for medical interventions. If consent is refused then any touching becomes professional misconduct or even assault. This fact appeared to come as a surprise to

some of the respondents in review of Part 5 of the 2000 Act (Davidson *et al*, 2004: 51) and while medical practitioners were not actually unaware of the legal position, 'it appeared to be a relatively insignificant factor in how they regarded the Act or Part 5 in particular' (*ibid.*). However, if patients do not know that they are being treated, by medication being concealed in food, for example, then they are neither able to consent to, nor refuse treatment. This may have implications for other healthcare providers who might be expected to administer medication covertly and without the patient's consent. Ultimately, giving treatment without seeking consent or without an Incapacity Certificate, by virtue of section 47, 2000 Act, may have an impact on carrying out the patients' prior wishes.

Similarly, this doctor states that discussion with the patient would only take place if the doctor thought the procedure to be 'potentially uncomfortable'. People who encounter or administer medical procedures on a regular basis can quickly become de-sensitised to the discomfort and pain involved. It is therefore of concern to determine by whose standards this potential discomfort is being judged. It would appear that, in this instance, respect for patient autonomy is being ignored for the sake of convenience and the smooth running of the NHS.

One oncologist stated it was important that patients were explicitly told about their right to refuse treatment.

I mean patients ... the way that we come to, particularly in Oncology, a decision about treatment is that the clinicians explain the pros and cons of various approaches because very often, particularly for palliative therapy, there isn't a clear-cut curative benefit, and what the patient wants may determine what would be the right thing to do and there are balances between benefits and side effects and costs and inconvenience and all of that. And patients' attitude and their wishes are a very important part of that equation (SD09).

Another oncologist did not advise them of this option and believed that it was the duty of the doctor or consultant to advise the patient only on the best treatment option.

A small group may not wish to take that advice and that's perfectly reasonable and no treatment is entirely an option, they may ask "what will happen if I don't have this treatment?" That is quite common, but it's a no treatment option ... as I said, it's not up front but I suppose it does occur in cases ... I think more widely, in cases of very advanced cancer, where no treatment may well be offered (SD08).

Oncologists interviewed who believe that patients should only be given the best treatment option are not giving patients all the available choices and are even withholding information through use of their specialist knowledge as power.

Conflicts in Decision-making

The power imbalance between doctor and patient may cause disagreements between the parties. When a patient refuses treatment and the doctor feels that the decision is wrong, the situation can be resolved in different ways. One method is through communication with the patient and close family, explaining the benefits and effects of the treatment.

Often the doctors interviewed stated that if there was a problem with a patient refusing treatment, a psychiatric assessment may be called for. The tendency to assume that the patient has a psychiatric condition if his/her choice of treatment or treatment refusal does not concur with the physician's was noted and advised against as far back as 1988, when an Age Concern report stated

The physician should not strive to regard an irrational decision as incompetently based [and] the physician should always be aware of the real possibility that a patient's values and goals may differ from his and so he should not necessarily evaluate an unreasonable or potentially damaging decision by the patient as stemming from an incompetent lack of understanding. A mere decision that is regarded as unreasonable should not in itself lead to a finding of incompetence (Age Concern, 1988).

In the case of patients recovering from strokes there may be fewer disagreements from relatives, but instead there may be more unrealistic expectations, one neurologist explained,

I think in my situation in the Rehabilitation Centre perhaps their expectations for improvement are ... they're disappointed. They feel patients should be better than they are and, from a therapy point of view, that's true ... rather

than us being able to give something, which is life changing or life saving or affecting the outcome (SD04).

Relatives often disagree with treatment decisions made by doctors, and one area where this may happen more than most is in oncology. The need to retain some hope of recovery for their relative can cause problems between family and doctor, and one oncologist was asked how this was resolved,

...patiently and in time. You really try very hard to find out why there is a disagreement and very often the disagreement is about some underlying agenda that is nothing, necessarily, to do specifically with the decision about treating them, whether it's about guilt and past relationships or whatever. You try to find out what it is that makes them disagree, then what is the gel in this decision and give them the opportunity to understand what are the reasons that there is this discrepancy (SD09).

No doctor interviewed suggested that they would consider the law or courts as a way of settling conflicts. Neither did they give any examples of relatives threatening or taking legal action against doctors or hospitals as a way of influencing treatment decisions. In the small sample of Scottish doctors interviewed, litigation against their medical decisions was not a current problem.

Advance Directives

Definitions

Advance directives have unproven authority in statutory or common law in Scotland although English case law (*Re C*, 1994, *Re AK*, 2000) is likely to be very persuasive in the Scottish courts as Scotland generally follows England at common law on medical matters (*Law Hospital*, 1996). Because of the small number of advance directives being used in Scottish hospitals how they were understood by Scottish doctors is exploratory.

Elderly

A reasonable, if simplistic, definition was given by a geriatrician who stated that he believed that the following criteria were all that were necessary to fulfil the term 'advance directive'. It was:

... where a person, [who] has capacity and competence to make a decision about their future care, comes up with a plan of management should certain circumstances arise in the future (SD01).

This basic definition was built upon by a second doctor for the elderly, who gave the example of a person with a progressive and incurable illness.

If somebody has Motor Neurone Disease and they decide that, in the future, "if I go into respiratory failure, I don't want to be put on a ventilator", and that that decision is made and written down ... [but] it doesn't always have to be written. An advance directive can be vocal but usually ... I would take it as being an informed decision where the person is aware of the risks and benefits of ventilation and of not having ventilation. Where it is a witnessed decision, ideally witnessed by a medical professional, that's the sort of idea I have about advance directives (SD03).

The last interviewee makes three points:

- The person must be aware of the risks and benefits of the treatment;
- The directive does not need to be written; and
- If not a written statement, then the oral statement should be witnessed by a medical professional.

These aspects recognise that the patient, by being aware of the risks and benefits of the treatment, must have had capacity when the directive was made. The acceptance of an oral statement as long as it is witnessed by a medical professional may be comparable with case law in England and the WGBO in the Netherlands and while it is only one doctor's view of the definition of an advance directive, it shows a willingness to respect an individual's autonomy as expressed earlier.

Witnessing the document or verbal statement was preferred by some doctors interviewed, but just as important was the desire for the doctor to discuss it with the patient. To say simply that the doctor was aware of the directive was not sufficient to confirm that the doctor knew that the patient was making an informed statement.

Sometimes patients can be misinformed and can say "I don't want this to happen under those circumstances." When you talk to them, you realise well, it's because of this, this and this, but if you point out all that is rubbish, "oh!" So I think it's I important that we know that they've been properly informed when they make that decision (SD10).

Neurology

Neurologists interviewed had a similar idea of advance directives, but also added two other factors. First, they raised the issue of legality, not that the doctor is legally bound by the directive, but that the patient would hope that it was binding.

My understanding is that someone makes an attempt to write down their actual wishes in the event of certain things happening and that they would wish that this could certainly be legally binding and that their wishes are respected and carried (SD04).

Secondly, that the directive is, in reality, a *refusal* of treatment, and not a demand for treatment against the doctor's better judgement.

An advance directive is any sort of document where a patient would write refusal of certain treatment because we know that people can't demand futile treatment (SD06).

Thus, neurologists interviewed appear to understand that the patient is making a serious attempt at retaining individual autonomy and that he or she believes the document will bind the doctor to these wishes. What the neurologists interviewed do not say, however, is whether they will accept its binding nature or even that they will follow the patient's directions. What they do make clear is, that the advance directive must only be used to refuse treatment and not as a way of asking for treatment, futile or otherwise.

Oncology

From the points of view of the oncologists interviewed, the advance directive (or living will) is defined in a similar fashion, with some unusual differences. One doctor believed that the directive is a written document that has only an advisory function, to appraise the physician of the patient's, or next of kin's wishes.

Well, I'd imagine it would indicate, in print, what a certain patient and/or her husband, perhaps, would wish to happen if they were in certain circumstances (SD07).

It is unusual that the doctor would believe that the patient's spouse would express his or her wishes in such a document. If the attending physician felt it this was necessary it would seem to be simpler merely to ask the spouse. The tone of the doctor's

statement implies that the document would only have an advisory capacity, which the doctor could disregard if s/he did not agree.

A second oncologist indicated that he thought the directive would only be advisory and that medical staff and relatives must agree with the specified course of action. Both these views are legally inaccurate.

I think that whether it's a document or whether it's an expressed view; patients have got the right to [consult] with their medical attendants of what would be the kind of shape of their terminal illness and what they would like to do (SD09).

According to the oncologists interviewed, most patients with cancer do discuss the course of their treatment as the nature of their illness usually gives them time in the process to develop that. One oncologist had had experience of a patient with an advance directive, and this type of arrangement worked well for both the healthcare team and the patient.

I understand the idea that a patient has clearly expressed a desire for a certain set of circumstances to lead to a certain set of interventions or lack of them and that that has been properly documented and made aware to the medical team, not just the consultants but the doctors and nurses looking after her, in advance. That is my experience. I've had one patient, a youngish woman, who clearly realised her days were numbered and she'd written what she called a living will and actually had it backed by a lawyer. It was very clear what she wanted, so that's my understanding of it (SD08).

The differing beliefs of the legality of advance directives among doctors interviewed in Scotland may be due to several factors. Doctors have a lack of experience in use of advance directives, there is no Scottish case law or any statutory authority on advance directives and many doctors disregard BMA guidance on the subject. All these problems lead to a misunderstanding of the law in this and related areas of medical decision-making. None of this helps patients in their quest to protect their right to respect for autonomy before or during their incapacity.

Use of Advance Directives

The extent of doctors' experience of advance directives is set out in the table below.

5.1 Scottish Doctors' experience of dealing with patients with advance directives

<i>SPECIALTY</i>	<i>ESTIMATED FREQUENCY OF PATIENTS WITH ADVANCE DIRECTIVES</i>
Care of the Elderly	~ 4% (some oral directives)
Neurology	~ 3% (some oral directives)
Oncology	< 2%

(Source: Interviews with Scottish doctors)

Few doctors have experience of patients with this type of anticipatory decision-making; therefore much of the information received from medical interviewees in Scotland is largely anecdotal.

Elderly

A specialist in care of the elderly had an interesting story regarding his experience of patients with advance directives.

This person had been a barrister and he had had a small stroke and then he was having further strokes and he made an advance directive that said he did not want to be ventilated or resuscitated or "if his mental state was such that he was not going to recover to making competent decisions, he did not want antibiotics in the event of a chest infection". He was in a nursing home and the directive had been made and was left with his GP who held a copy. When he came in to hospital he had a bad pneumonia and so the GP had said "I have this advance directive", and gave a copy of it to us, so we were bound by that because we felt that his quality of life prior to coming in, was so poor; he was bed bound and had pressure sores, etc. But his daughters came in they wanted him to be ventilated. Well, that one example that took so much work and effort on behalf of staff on the ward, the professor, me, the person's family, and lawyers (SD01).

This case occurred in England but gave the geriatrician an insight into the difficulties that could arise with an advance directive that was likely to be drawn up, considering the patient's background, as accurately as possible. The doctor was made aware of the problems that could arise when the family objected despite the fact that the relatives had no legal rights in the matter and the advance directive was valid. In this

situation, the directive was respected, but not without a lot of time being spent on the entire circumstances by the healthcare team and the family.

Neurology

Patients often use oral directives; an example arises from a doctor who worked with stroke patients in a neurological unit.

I had a recent example where one of my patients had said to her friends, and she'd been a nurse, "I would never want to be tube fed" and since her stroke, had become dysphagic and had refused tube feeding but she was dying of starvation and she was hungry and we talked to the family about going against her previously expressed statement? The problem is, of course, the person who made that decision was the healthy lady, independent, roaming round Scotland and [enjoying] foreign holidays. The person who needed the decision-making was a lady with only half a brain, who was very disabled in a hospital bed and that person is now different to the person who made the decision. And she could communicate. And when we actually gave her the prognosis, that she was going to die soon with or without a PEG [percutaneous endoscopic gastrostomy] tube feeding but with peg tube feeding ... she wouldn't die of starvation, she then decided she didn't want to die and accepted a PEG (SD02).

As this doctor explained, this is one of the medical profession's problems with advance directives. People may die without changing their minds, but also there is the issue of who made the best decision: the person in her previous state, with a shortened period of disabled life or the currently disabled person who may be able to have further contact with her family over the next few months or perhaps years?

I don't know, ethically, on quality of life issues, if she's made the right decision but certainly she made a different decision in her disabled state than she's made in an independent state (SD02).

Another neurologist interviewed also had experience of advance directives, but seems to have had fewer problems with them than his colleagues.

In my experience, they're not common at the moment in practice. Some of our patients have told me they have had them and they've told me what's in them and it's come across when I've talked about CPR [cardio-pulmonary resuscitation] decisions and some people have said they would never want intensive care or tubes to keep them alive, artificial ventilation. So, yes, I've come across them and, as I say, it's been very helpful for CPR decision-

making, which is a universal policy we have to think about for every patient (SD05).

Oncology

Only one oncologist interviewed had had a patient with a written living will, but most had patients who had very strong views about what they wanted and did not want to have in the final part of their life. Some patients had expressed these views in the format of an oral living will, which might be taken into account but could cause problems if any conflicts arose. Oral directives have been debated in the medical literature but their inherent problems are compounded by 'the paucity of legal and ethical guidance on reported oral advance statements makes debate imperative and renders the alternative of having designated surrogate decision makers increasingly attractive' (Sommerville, 1995: 1663).

One doctor believed that if more people did have their wishes written down for use at a later time as it could make his job easier. It would make it clear where the difficulties are, and how they might be approached.

We're debating it at the moment with the directives about not resuscitating and CPR, which, in a Cancer Unit where at least a third of our patients, are here because of palliative care and are clearly dying, it adds another dimension. In the past we would not necessarily discuss it with them explicitly, but decisions would be based on joint understanding of what is a reasonable thing to do for that patient in those circumstances. Now that we have to discuss it with some patients directly, it is actually much easier than we thought it was going to be. In a way, patients are actually relieved that they can say, "No, I don't want to have to go to the ITU [Intensive Therapy Unit] and have tubes stuck in me and be put on a ventilator" (SD09).

While few doctors interviewed had experience of advance directives, either in writing or as oral statements, the majority of interviewees in Scotland were able to see the advantages that might come from them being adopted more widely. There may be resource problems where more time is required to be spent discussing decisions with patients and relatives, but the doctors interviewed appear to be aware of this. Advance directives were mostly seen in care of the elderly and neurology, but were still very rare. Oral directives were often used and discussed with doctors in oncology. The majority of doctors felt that their greater use, whether in writing or verbal, would be helpful for doctors in future decision-making.

Hospital Admission

According to the doctors interviewed, patients admitted to Scottish hospitals are generally not asked whether they have an advance directive. Answers given by doctors in each of the specialties are outlined below.

Elderly

For doctors in care of the elderly, the question was simply not asked and there was an assumption that if a patient did have an advance directive, then either the patient or a relative would make someone aware of the fact.

It's not a standard question. I'd say if people have them, they would usually say it or relatives would say it (SD01).

Neurology

The situation was similar in neurology,

It's not something you'd ask. I would have thought ... if somebody has such a document, they're likely to let someone else know ... if this happens, I want you to ... (SD04).

The closest that any doctor interviewed got to asking patients in neurology was,

I often ask when I'm sitting down with the families, what the patient thought and that would often bring one out, if even they know about it (SD06).

Oncology

For oncologists interviewed, one doctor was clear; patients were not asked because treatments were discussed with patients. There also was the assumption that the patient would let the doctor know if s/he had an advance directive.

I don't ask patients. We tend to talk about the immediate treatment options and I usually give them some idea as to whether or not there are subsequent treatment options but I've never gone to anyone and said, "Do you have a living will?" My presumption is that, if they had one, they would bring it to my attention (SD10).

It is clear from all the medical interviewees in Scotland that the onus is always on the patient or his/her relatives, to inform the doctor of any advance directive or living will. Lack of experience in dealing with advance directives by practitioners in both

law and medicine and without any legislative developments, means it is unlikely that this current practice will change in the near future.

Legality

Scottish doctors who were interviewed were not well informed about the legal status of advance directives. They generally did not have any definite answers, and those they did have were vague with an indication that advance directives would be taken into consideration but only on an advisory basis.

Elderly

In care of the elderly only one doctor interviewed believed advance directives would be legally binding on his decisions.

Legally binding? I know that I would weigh up each one individually. Yes, I would certainly take it seriously, enough so that if I wanted to go against it, I would contact my Legal Department in the Trust or my Medical Protection Society and say that this advance directive has been made. Am I bound to follow it? And if there were three advance directives on three different patients in a row, and I disagreed with each of them, I would contact the Legal Department about each one. In other words, yes, I would say I'm legally bound so I would have to contact my legal side if I wanted change (SD03).

This was the only Scottish doctor who considered that they were binding on his decisions, others interviewed in elderly care were less sure of their legal status.

The advice that I last read was that I needed to take any advance directives into consideration but they were not legally binding under Scottish Law (SD01).

This doctor could not say where he had read this information.

Neurology

Neurologists interviewed were unlikely to find advance directives legally binding, but they were prepared to take them into consideration in treatment decision-making. This also applied to oral statements for future treatments,

If it was reported by a reliable person, I think I would. It then comes back to what was their state when they made that [decision] and do they know, for instance, that many strokes are not severe and they get better. The problem is that somebody may need to be fed with a tube for three weeks. They then stop needing that and get back to where they were SD06).

Oncology

As with the other doctors interviewed, oncologists were unsure of the legality of advance directives, but in one doctor's case this was inconsequential.

I don't know what their legal status is. Given that the circumstances under which I would expect them to be applied would relate to patients who are known to have a cancer and know that it is incurable, I would place a lot of moral weight by that decision (SD10).

As far as this oncologist is concerned if a patient needs an advance directive, and we need to assume that this would be a negative directive, the patient would probably not be receiving any further treatment in any case, therefore the advance directive would be unnecessary. This situation may be satisfactory for oncology, but it is a narrow view that would not be suitable for other medical circumstances. Those that come to mind are the incurable, but not terminal illnesses, e.g. motor neurone disease, Huntington's disease, Alzheimer's disease. All these illnesses require extensive treatments that the patient may wish to consent to or refuse sometimes where a refusal could lead to the patient's death. The problem being that without an advance directive the patient may not be able to refuse any or all treatments prescribed by the doctor.

Alternatively, by establishing rules surrounding anticipatory decision-making, one doctor believed that this was not necessarily a move forward.

I think that the more we actually make this legalistic and we get other parties involved, the more we decrease the quality of care for patients. I think it's unhelpful (SD09).

This statement begs the question – unhelpful for whom? The answer that comes to mind is that it removes the ultimate decision-making capacity from the doctor; therefore it would be unhelpful for the medical practitioner.

Overriding an advance directive

There may be many reasons behind doctors disagreeing with a patient's wishes for his or her treatment. For patients who have the capacity to make treatment decisions, the common law states that doctors may not override these wishes (*Re MB*, 1997 at 549). In Scotland there are no unqualified legal rules (common law or statutory) that prohibit healthcare providers from overriding a patient's wishes if he or she has lost capacity to make those decisions. In the case of advance directives, whether expressed orally or in documentary form, there also is no law that states a medical practitioner must follow them. However, there may be an implication in the 2000 Act that respect for a patient's present and past wishes could include those wishes written down in an advance directive. Additionally, recent English case law has stated that a refusal of treatment, in the form of an advance directive and provided certain criteria were observed, would be effective.

It is, however, also clearly the law that the doctors are not entitled so to act if it is known that the patient, provided he was of sound mind and full capacity, has let it be known that he does not consent and that such treatment is against his wishes. To this extent an advance indication of the wishes of a patient of full capacity and sound mind are effective (*Re AK*, 2001).

The doctors interviewed were asked to relate any circumstances where they thought they would be persuaded to ignore an advance directive and go against a patient's treatment wishes.

Elderly

In elderly care interviewees the main reason doctors gave for overriding an advance directive was if it was used to ask for futile treatment. It is widely acknowledged that doctors cannot be forced to give treatment they believe to be unnecessary, or which may be worthless in terms of improving the patient's medical condition. Therefore according to geriatricians interviewed, an advance directive which stated "I want everything done", when the doctor knows that any further treatment was futile, would be worthless and the doctor would be within his or her rights to ignore it. One doctor said,

I could say, "Well, they say they want everything done but it's futile". I would get a second opinion because it would be going against [the patient's wishes]... What I would do is say, well, it's my opinion that giving an antibiotic is not going to affect the quality of this person's life. It is only going to prolong their condition temporarily (SD02).

This scenario is typical of a positive advance directive where patients would use the document to ask for treatment and in contrast with a negative, refusal directive where it would be used to refuse further treatment. The requirement that an advance directive must refer to a treatment refusal in order for it to have any real influence on treatment decisions was true until a recent decision by the Administrative Court in England. The court found that GMC guidelines to doctors on withdrawing artificial nutrition and hydration (ANH) breached a patient's human rights (*R (on the application of Oliver Leslie Burke) v. GMC* [2004]). This ruling ensured that Mr Burke, who is suffering from a progressive disease, if he requires ANH, could only have it withdrawn after referral to the courts. This case is likely to have repercussions for positive advance directives which specify treatments that doctors may regard as futile.

Neurology

Reiterating what was said concerning the legality of advance directives, but still respecting their bearing on a patient's wishes, a neurologist stated

I wouldn't go against an advance directive unless there were serious reasons to do so and perhaps even get a second opinion ... I would not accept them as legally binding but I would treat them very seriously (SD05).

Alternatively, another neurologist was prepared to override the patient's statement if he strongly disagreed with it

... in general I think advance directives, if written before something's happened, are going to be non-specific because the person cannot predict what's going to happen, what the situation will be. If a patient has got a progressive problem or a problem which will lead on to another more predictable problem, then I think we could take more notice of that advance directive than one which is a new situation. So I think what you're trying to do is get at what the patient would want in full knowledge of what situation they're in now and of course you cannot do that directly (SD06).

It seems that this neurologist did not wish to ignore the patient's wishes, but was more concerned that the necessary wideness of advance directives may make them less authoritative as a method of controlling treatment decisions.

Oncology

One of the oncologists interviewed addressed the issue of overriding an advance directive from the perspective of being the person caught between patient and family members. This is an important issue, as there can be unrealistic expectations from the family that every treatment would be attempted. In these circumstances, the doctor must decide how he or she will proceed – by following the patient's wishes as expressed in the directive, or by conceding to the family's wishes to continue with treatment. A reasonable approach to this dilemma is expressed below by one of the oncologists interviewed,

I would, primarily, give a lot of credence to the living will. So if it was very clear to me you had written down "look, under these circumstances, I don't want treatment x" it would be your views that would be respected. What we would do is explain to the relatives why we were taking that view. Now if they said to us 'well, I happen to know that the day she wrote that, she was totally depressed' or 'completely drunk' or something like that, OK, then we would probably have to start to reassess it but, as I said, if I was aware one of my patients had written a living will, I would try and discuss the contents with the patient. So then I'd say to the relatives "look, actually, s/he may have written it when she was drunk, but I talked to him/her when s/he was sober and I know that's what s/he told me." So we would put a lot of weight by it (SD07).

Continuing, this particular oncologist was aware that not all situations could be planned and that these are probably fairly artificial scenarios. Ultimately, there may be no other solution but,

... to give my best advice, which if it coincided with the patient's previous expressed advice, I'd explain, if they were unhappy, I'd suggest we get another doctor (SD07).

Caught in a dilemma, this doctor was happy to consider the advance directive, but when the patient's wishes were different to the doctor's, he would probably pass the patient to another doctor. The concession to the family's wishes is unnecessary as is the need to pass the patient to another doctor if the family disagree. This could be

seen as abandoning the patient because the family disagree with the doctor. This is legally unnecessary because if the doctor and the patient agree on a course of action (by advance directive or otherwise) the family's wishes are immaterial and no other doctor's opinion is required.

Patient Autonomy

While most of the doctors interviewed did not believe that advance directives were binding, they did feel that directives might influence their decision-making and some thought they might have an impact on the protection of patient autonomy.

Elderly

In care of the elderly, all doctors interviewed felt that the patient's previously expressed view was, by and large, the most important issue. They hoped that their main concerns would be with the patient and that the patient's clearly expressed preferences would take priority. Additionally, they sympathised with the patient's family if they did not agree with the patient's decision, but would remind them that it was neither his/her nor the family's decision; *'it was their loved one's decision and they need to accept some things in life that are sad'* (SD02).

In the case of a degenerative condition, for example, Motor Neurone Disease or Alzheimer's disease, finding out, at the very early stages of the disease would usually mean that the person has insight and capacity to make a decision regarding future treatment. This doctor believed that this was relevant,

If a person decides "I have been diagnosed with Motor Neurone Disease and I don't want to go through the horror of all my muscles wasting away and now I want a decision made ... I don't want antibiotics if I am unable to move my arms or legs, I don't want to go on a ventilator." Yes, I would respect that (SD01).

As far as being useful in protecting human rights, the apparent feeling among geriatricians interviewed was explained by one doctor.

As a geriatrician, I think our speciality is much better at saying "enough's enough, let's bail out of this situation." Whereas I see some of my single organ specialist colleagues persevere to the bitter end. An advance directive

might improve some people's terminal care, maybe but perhaps the Human Rights Act will be sufficient (SD03).

This interviewee has raised a relevant point as the Human Rights Act 1998 is designed to protect a citizen's rights from being eroded by the state. As representatives of the state hospitals will be liable if an individual's or a proxy's rights are ignored or eroded in some way by hospital policy or medical decisions made on the state's behalf. Since there have been no court decisions on advance directives in Scotland, individuals may have to rely on actions raised under human rights legislation.

Neurology

All the neurologists interviewed would be less inclined to treat people with severe cognitive problems than to treat persons with severe physical problems. This is because cognitive problems are unlikely to recover and are more likely to be progressive and therefore physicians are less uneasy about not treating them than a physical problem.

I think the ability to absorb and cope with physical disability is greater, by definition, than the ability to cope with a cognitive disability (SD06).

Neurologists interviewed were also positive in their belief that advance directives would be helpful as one method of retaining a person's autonomy in situations where patients could not speak for themselves. One doctor had views on how that protection could be improved upon,

I think yes, they do bear on one's decision-making and therefore they help you along. I suppose they could be made more useful by being very explicit but they would need, guidance, not of a lawyer, but of a doctor to explain to them, the sorts of common situations they might end up in and the prognosis from there on. So, for instance, if somebody, prior to becoming severely demented, had the implications of dementia, and the fact it is a progressive thing, explained to them and they signed a document, which says "look, I understand all of this and if I get to that state, I don't want to be fed", then I think I would take more note of that (SD06).

They also believed that advance directives were a suitable method of safeguarding someone's individual human rights. One doctor qualified this by arguing that the nature of the advance directive and what it contains,

I think, in this country ... we live our life, not expecting things to happen so we think there's no problem. People may develop a certain disease process and they then make a directive, with regard to that disease process and it may be very specific to that (SD04).

While neurologists interviewed thought advance directives useful in retaining patient autonomy and human rights, previous questions established that neurologists interviewed did not think advance directives were legally binding on doctors. Advance directives, as methods of protecting individual autonomy and human rights would still only be effective if the doctor agreed to follow them. If the doctor did not agree with them, did not believe they were binding on his or her decisions, and therefore felt justified in overruling them, it would be of no consequence that they could protect autonomy and human rights, as they will not have the opportunity to do so.

Oncology

On the other hand, oncologists interviewed were less sure that advance directives would be useful in retaining patient autonomy. While one doctor did agree that they were important, especially if the patient is concerned about their autonomy in the future, advance directives may not be as important as some people think.

I try and make patients feel that they retain autonomy in decision-making. I suspect if you interviewed half my patients, probably some of them would say "no, I don't feel I had that much autonomy", and obviously that's my failing, but I think the need for a living will comes when the patient feels they don't have autonomy but there is something they draw a stand about: "I want to make that decision." I, and most oncologists I know, do try and allow patients to be involved in the decision-making and therefore I wouldn't expect many of them would feel the need to have living wills (SD10).

This doctor continued by expressing a hope that his patients had enough confidence in the health service to feel that they were involved in decision-making, and that they felt part of what was going on. Consequently, when it comes to making another decision, then their wishes would be respected, if the patient were still competent to make a decision. However, there would be no need for an advance directive at this point and the doctor seems to misunderstand when the directive is required. Whether or not the patient feels autonomous is irrelevant if he or she still has decision-making

capacity. The advance directive will only come into play when the patient has lost capacity to make decisions. As has been mentioned in many of the oncologists' responses, by the time the patient becomes unable to make a decision, in the majority circumstances there is no decision to be made because the treatment regime has already been decided between all parties concerned. In this oncologist's view *'the number of instances where more living wills would make my life easier would be very few'* (SD10).

Conversely, another oncologist felt more strongly that advance directives were a suitable way of safeguarding patient autonomy. Although she did hope that patients' rights, including respect for their autonomy, would be safeguarded throughout their treatment and that a situation where an advance directive might be required would not be so common however,

It does assist in that process but I think it's a mistake to see it as the main thing to preserve that right. It should be preserved all through the treatment and clearly if a patient who is incompetent prior to their illness, like somebody who is very badly brain damaged, then they may never have had the opportunity to write a living will. There may be a few who have but what happens all along, I suspect, in those patients, is that you would involve their carers, their relatives and most of the time they have their best interests at heart. So yes, it is a safeguard but I don't think it's the most important one (SD08).

The difficulty arose for oncologists interviewed when the patient had stated in an advance directive certain conditions of treatment, but for whatever reason the doctor was unable provide treatment. In this situation legal advice was felt to be important and,

a situation where a living will would need to be legally sorted out because if a patient is saying "well, look, I'm prepared to die to have no pain" and yet I know that I can cure them, our natural inclination, as doctors, would be not to take that risk. So we would need the legal standing sorted out. But for the patients I treat, there isn't an issue (SD07).

Finally, using advance directives to protect certain human rights was anathema to one oncologist.

I suspect it might do exactly the opposite. I would really be concerned that if it becomes a statute, then what will happen is that, unless it's there, people will then go, in their self-protected way, to explore the lengths to keep somebody alive and then it may just misfire because patients will fall through those gaps (SD09).

In other words, this oncologist believed that doctors would play it safe, and unless a patient had an advance directive, they would keep patients alive for as long as possible for fear of being sued.

Conscientious Objections

Many doctors have connected conscientious objection to opposition to advance directives, whether on religious³¹ or moral grounds. The BMA has issued guidelines regarding conscientious objections to advance statements for doctors and patients on this matter (BMA, 1995a) and advises that if the doctor does not wish to treat a patient who has written an advance directive, he or she must ensure that the patient's care is passed over to a doctor who has no objections. These statutes, codes of practice and guidance are relevant to doctors practising in all jurisdictions of the UK and especially applicable to the analysis of English doctors' interviews in Chapter Six.

Elderly

In elderly care, the interviewees were generally in favour of doctors being allowed to withdraw their services. They felt that it would be reasonable for a doctor to object to advance directives in a similar fashion to their objection to participating in abortions, especially if the directive was binding in law.

I think doctors should have the right to withdraw and to ask another doctor to take over care but again, it should be done with ... preserving the doctor's autonomy as well. Yes, it's similar to should a Catholic doctor be made to perform abortions? It's similar, but not the same ... doctors in other areas have the ability not to do things if they disagree with them. If you are not prepared, ethically, to deal with a situation, you need to refer to someone who is ethically prepared to deal with the problem. I think if they were legally binding, I may have trouble with advance directives (SD01).

³¹ See The Guild of Catholic Doctors, 1984, *Proposed Code of Practice on Advance Directives or Living Wills*.

Neurology

A neurologist who was interviewed did not believe that it was reasonable for a doctor to object to advance directives on ethical grounds. He felt it unreasonable for a doctor to use his or her personal objections to refuse to carry out patients' wishes. The patient may want the doctor to stop treatment and conveys this wish via the advance directive; however, the doctor may have moral or ethical grounds for objecting to withholding treatment e.g. ANH. In this neurologist's opinion it would be wrong to impose these objections on the patient and continue to treat regardless. He said,

I don't think so because, even if you come down to just the basic medical theorem, we are not allowed to do anything without the individual's consent. We can't operate, we can't stick a needle in them, if we do, it's termed assault. They have to give consent, so if somebody refuses to have a blood test, there's nothing we can do about it, and you cannot get that blood test. I think this is perhaps an extension of saying "I do not wish you to do that." I think the majority of individuals would say "well, that's just, that's their decision. But some people may feel it has to be done (SD04).

The doctor believed that when the patient refuses consent through a living will or advance directive and this refusal would eventually harm the patient, the doctor who objects to this refusal must transfer the patient to another suitable neurologist; otherwise the doctor is committing an assault by treating the patient against his or his will.

Oncology

Doctors interviewed who specialised in cancer care held similar views. One stated that by '*treating patients in the National Health Service one should be prepared to take patients of all sorts*' (SD07).

Another oncologist interviewed who dealt mainly in palliative care gave a more detailed view. He did not believe that the patient's view should be disregarded in favour of a doctor's opinion.

No, I don't agree, a lot of my work involves patient decisions. None of our treatments are 100% effective so every time I discuss a treatment with a patient, I have to introduce to them the uncertainty as to whether the treatment will work or not and therefore the patient has to, at least, have the

opportunity to be involved in making a decision as to whether or not they want the treatment, so I depend on patient interests. One patient will make a different decision in the same circumstances to another. Fine, they're different people. The same applies to whether they've got living wills, so I cannot see why you could object to them having a living will (SD10).

This oncologist understood that doctors in other areas of medicine may have a different outlook, for instance those working in Accident and Emergency Departments who see their jobs as putting people back together and saving their lives.

I can imagine those kinds of people would have a problem with [advance directives] because they might say, "well, does a patient really know what they're agreeing to?" But I think if a patient is properly informed ... after all patients usually come to the doctor in the first place, they've made that choice, so why can't they make other choices (SD10)?

From all the doctors' responses, conscientious objection to advance directives is less straightforward than it initially appears, and can operate on several levels. Some doctors felt that being able to circumvent the use of advance directives on religious or ethical grounds seems to be only fair on the basis of professional autonomy. Conversely, if the advance directive is to be viewed as an extension of patient autonomy, as a facility by which to control treatment decision-making, then a conscientious objection by the doctor will be a type of erosion of the patient's autonomy: a case of professional versus personal autonomy. A compromise may be to ensure that a doctor with no such conscientious objections can treat the patient, and this is probably what the BMA intended by issuing the aforementioned guidelines. Nevertheless, by only making these guidelines advisory, there is no strict duty on the doctor (as the most powerful partner in the relationship) to follow them.

Conclusions

In Scotland, statute law (in the form of the AWI Act) and the common law govern treatment consent. Informed consent from all patients with capacity is required before treatment can be given; this consent may be implied, as may a refusal, usually through shunning approaches to give treatment. The doctor may restrict the treatment options available with no duty to inform the patient of available treatment choices.

The right to refuse treatment cannot be overruled, but there is no duty to inform patients of their right to refuse, they are usually only asked about CPR decisions.

Doctors interviewed in Scotland appear to be unsure of the law in relation to issues of consent and erroneously may ask relatives to consent to treatment. In all cases, treatment decisions for patients without capacity are made using the best interests model of decision-making.

Medical authority is held in high esteem according to both doctors and lawyers interviewed in Scotland. Doctors hold a position of power and both patients and families respect their decisions. Challenges are evident in the unrealistic expectations held by families, poor communication with the health team and through doctors withholding information from patients.

An advance directive is perceived by medical practitioners interviewed as being a plan of management of the patient's future care and a refusal of treatment only. Lawyers interviewed do not regard directives as being legally binding on doctors and only one doctor was prepared to view a directive as binding in decisions. The majority are only prepared to take both written and oral directives into consideration. Doctors will override a directive if they feel it necessary and if the directive is irrational. Some doctors interviewed would only consider advance directives and will follow them only if not against doctors' decisions.

The general opinion among doctors interviewed is that use of advance directives is a move away from paternalism and that they could be useful in promoting the patient's personal autonomy. While safeguard are sometimes necessary because of struggles between professional and personal autonomy, there is a chance that directives might restrict the doctor's ultimate decision-making powers and therefore should not be given statutory authority.

Chapter Six Analysis of English Data

Introduction and Background

This chapter adopts the same design as Chapters Four and Five, which examine the same issues from Dutch and Scottish perspectives. Lawyers' and doctors' views on treatment decision-making and advance directives are explored and how they affect professional and patient autonomy is discussed.

Ten lawyers and ten doctors were interviewed in England, all interviews were in-depth, qualitative, and semi-structured, lasting in the region of 30-50 minutes each; analysis was conducted using NVIVO qualitative data analysis software, and the discussion highlights how advance directives are affected by the current English legal arrangements

This chapter shows that treatment decisions for patients with capacity in England are generally made after discussion with the patient and sometimes with the family. It is recognised by all parties interviewed, however, that while competent, the patient always has a right to refuse treatment regardless of the consequences. This right is not always explained to patients on their admission to hospital for treatment. For patients without capacity, the healthcare team will normally make decisions on their behalf through discussion with relatives and colleagues and also by referring to the person's earlier wishes made known by oral or in written advance directives. Different doctors use different decision-making models: usually substituted judgment or best interests models. Conflicts are resolved through discussion with all interested parties.

Neither doctors nor lawyers believe that advance directives have binding legal status on doctors at present in England. New legislation may provide some protection for patients' autonomy as the Mental Capacity Bill introduces advance directives into English statute law. Lawyers are more likely than doctors to believe that the courts

may continue to rule in favour of advance directives becoming binding on doctors in the future.

Generally, while the *capax* patient has ultimate decision-making power over medical treatment, the *incapax* patient only has protection over his or her autonomy through advance directives. These directives are currently regulated through Codes of Practice but may be given statutory backing in the future. Likewise, patient autonomy is less protected than professional autonomy and the resultant balance of rights is more heavily weighted on the side of the healthcare professional than the patient.

Lawyers

Ten English lawyers were interviewed, all working in the areas of private law, reparation and negligence, wills and probate, trusts, estate and asset protection planning. The lawyers worked with private clients in or around the Newcastle and Sunderland areas, and all gave permission for the interviews to be tape-recorded. These pursued two main themes: English legal arrangements in treatment decision-making, and lawyers' opinions concerning advance directives under current law in England.

Legislation

Background

The Draft Mental Incapacity Bill (Cm 5859-I) and accompanying Commentary and Explanatory Notes (Cm.5859-II) were presented to Parliament on 27 June 2003 by Lord Filkin, the Parliamentary Under-Secretary of State for the newly created Department for Constitutional Affairs. The draft Bill is the result of a lengthy and detailed process of consultation. In 1989, the then Lord Chancellor, Lord MacKay of Clashfern, invited the Law Commission of England and Wales to carry out a comprehensive investigation of all areas of law affecting decisions on the personal, financial and medical affairs of those who lack capacity. This was in response to concerns raised by professional bodies and voluntary organisations dealing with

mental disability. Following five years of consultation, the Law Commission produced its final report and recommendations for Law Reform in March 1995 (LC, 1995). The Commission recommended that ‘there should be a single comprehensive piece of legislation to make new provision for people who lack mental capacity’ (*ibid*, Summary paragraph 1.2).

The Bill will govern decision-making on behalf of adults, both where they lose mental capacity at some point in their lives, through, for example dementia or brain injury, and where the incapacitating condition has been present since birth. It covers a wide range of decisions, on personal welfare as well as financial matters and substitute decision-making by attorneys, a court, or court-appointed “deputies”, and clarifies the position where no such formal process has been followed. If necessary, the Bill will provide an opportunity for a court to deal with all personal welfare (including health care) and financial decisions on behalf of adults lacking capacity.

Clauses 23 to 25 of the draft Bill set out the circumstances in which persons with capacity, having reached the age of 18, may express in advance a decision about what treatment they would wish not to have if they were subsequently to become incapable.

Until the Mental Capacity Bill is enacted and comes into force, legal authority surrounding decision-making for patients with incapacity continues to be based on common law. Several cases involving medical decisions helped mould the law but some lawyers interviewed had opinions on how patients were characterised by the law and by doctors. One lawyer felt,

I think, personally, that the law doesn't take into account very much the autonomy of the patient and it's an area that I've got a lot of feelings about. I think they [doctors] still play the paternalistic role to a great extent (EL02).

The legal reality is that the courts, in their judgements, do take patient autonomy seriously and acknowledge that anticipatory decision-making is authorised by law. For example, a non-written advance directive made by a young man with “locked-in” syndrome was held to be effective,

To this extent an advance indication of the wishes of a patient of full capacity and sound mind is effective, but care must be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient (*Re AK* [2000] per Hughes, J).

The lawyers interviewed agreed that nobody in England could consent on behalf of the patient,

... no other adult can consent for another adult. It has to be the doctor [who] takes on the responsibility if [patients are] not capable of making their own consent (EL05).

Or more fully,

If I came across a situation where somebody who was saying a loved one was in hospital and it was said that medical treatment was required but the person was unable to consent to that treatment and what were they to do about it, I'd have to check it really, look into it carefully. My understanding is that the doctors can take a view about the capacity of the patient and can override the patient's own right to consent by saying the person is not capable of giving consent and therefore they will go ahead with it on the basis that it is a reasonable and necessary procedure (EL01).

Type of Law

Compared to the Netherlands, where medical decision-making is given authority by statutory law, medical decision-making in England relies on common law doctrine and case law. Several important cases have shaped the law on advance directives and medical decision-making *incapax* patients.

At present people's misunderstanding of the law in this area has caused problems for family members who may approach lawyers because they are unsure of the law regarding consent and refusal of treatment for their incapacitated relative. One lawyer gave an example of how people misunderstood the law,

They still think that they can make decisions on behalf of other people and I think that's something that probably, as time passes, will get better or will change ... and I think it's just something that people think they have the right to do, is to make decisions for other people (EL03).

The advice given by lawyers usually involved recommending further discussion with healthcare practitioners and it would be rare for the problem to require recourse to litigation.

I have had discussions with people who have contacted me by telephone, concerned about it. It's never been followed through in terms of a serious issue. There was a recent case, I think it was in Newcastle, I think it was relating to consent to treatment ... When people make an enquiry with me, I start off on the basis of the importance of communication so that the patient's relatives should ... try to communicate fully with ... the treating doctors (EL10).

In dealing more specifically with law in the sphere of advance directives, one lawyer gave his reasons for appreciating the current status.

The law surrounding medical decision-making on behalf of those who are incapax is not governed by statute in the United Kingdom. I see this as advantageous in that the granter of a deed containing an advance directive is effectively making an anticipatory decision, at a point when the facts regarding his future condition and the treatments available to him are unknown, about medical treatment which will or will not be received by him. I feel that the rigidity of a statutory framework in this area may make it difficult to maintain the necessary flexibility with regard to treatment which is demanded by such an unpredictable factual nexus. For example, it would, I think, be counter-productive for a doctor to be legally bound to act in accordance with a living will despite having strong reason to believe that the patient would not have wished it to be adhered to in the unforeseen factual circumstances arising (EL06).

Because of the present lack of clarity, the Mental Capacity Bill is anticipated eagerly, but regardless of the absence of statutory rules, lawyers encourage families to talk to each other and to healthcare professionals in an attempt to understand and resolve any problem areas.

Case Law and the Courts

As mentioned in the previous section, the common law in England and Wales is the dominant form of legal authority for medical decision-making. The lawyers interviewed found the common law to be appropriate to medical decision-making, one expressed her opinion,

The common law is what I work in and I find it flexible, [there are] things that you don't like because it's not specific and it's not clear but there is flexibility and there is room for manoeuvre and there is all that sort of stuff, which is very good. Of course the bad side of it is lots of time it depends on judicial discretion and judicial interpretation but statute is not the be all and end all because there are an awful lot of difficulties about statute, and statute is as good as its drafting and a statute very often doesn't fulfil what is required. You look back and you think, well actually we needed more in this statute. We needed different things. So should it be enshrined in statute? No, I don't think it should. I think there should be a House of Lords decision about a living will, which is a horrible thing for the people who are going through to go through but I think that would be the way (EL05).

Some lawyers interviewed believed that doctors might prefer there to be some type of statute law, central to this area of medical law. It might afford greater clarity enabling clinicians to base their decisions on a more solid footing.

I don't know about making it easier, it would probably make it clearer because of the decisions that have to be taken. It may be that a lot more people would object and not want to be involved in them. ... Yeah, there might be more people who would say "I don't want to be involved in that" but certainly ... it would be like a protocol. As long as you followed the protocol, you would be covered by that, where I think, at the minute, people say, "oh, well, I don't want to make this decision because I don't know how I stand" (EL09).

It seems, from this statement at least, that this lawyer sees two issues: first that there is a lack of clarity surrounding the law, where the confusion lies is not absolutely clear, it may be among the doctors or the lawyers or the relatives, or even all three. The second point is that if there were more definite rules then perhaps some parties might not want to be confined by these rules. Again, it is not clear which party this lawyer thinks might object most.

Of the three jurisdictions investigated, England and Wales have produced the largest number of court actions in decision-making and living wills. Major sources of court action are cases where relatives and the doctors disagree about the treatment regime for the incapacitated patient.

Difficulties do arise when the relatives disagree with [the doctor] and they want treatment continued to be given and then they come and see the lawyer

and at that point you have to explain to them "well, you can't force the doctor to treat". I think one of the problems is that the law is viewed, I think, as an adversarial system, as a fight. Whereas I don't think in these sorts of cases that it necessarily needs to be so. I think there is a lot to be said for doctors being upfront and straightforward and just saying, "we think this". If you, as the relative, disagree well, it's like a form of mediation. The effect is to go into the High Court with both of their arguments and whatever the outcome, we will abide by it. But I don't think doctors are often that grown up. They tend to say, "this is what should happen", and they get very uptight when the relatives disagree (EL03).

While this lawyer saw court action as a problem-solving arena, he had the impression that doctors did not agree. It would appear that this lawyer felt that doctors would react badly to a court action and possibly would feel that their professional authority was under attack.

One lawyer also mentioned that legal aid might be a problem that could arise when the courts became involved,

If the patient is eligible for funding, then the relatives may not get funding. But the patient, if they're incapable of making a decision, would be represented by the official solicitor whose only instruction is really arguing for the patient (EL08).

Problems may arise for people without adequate finances to fund an action in court to decide whether to follow a patient's advance directive. Without clear, possibly statutory guidance, many people will be unable to contest medical treatment-decisions and this may also infringe their rights to distributive justice.

Capax Patients

All lawyers interviewed concurred with doctors on the principle that a treatment decision made by a patient with capacity could not be overridden regardless of the consequences. One lawyer mentioned that in some conditions capacity may vary from day to day, for example, in organic brain disease (dementia, Alzheimer's Disease, etc.) a patient may become lucid for extended periods before returning to a less aware state, consequently decisions may be taken on that person's behalf from time to time,

I mean there's some days I could say I probably haven't got capacity if I'm feeling tired or if I'm spaced out and I have a "senior moment" because I'm at that age and you think, well, yes, because I'm exactly the same. So who's to say that I've got total capacity all the time? And I'd hate for someone to say, "well, I've decided on your behalf" when, in the next ten minutes, I could have capacity back again? So, yeah, I think it's a big area that needs to be looked at (EL09).

Capacity therefore, may not always be clear cut and can cause problems for autonomy. The courts are not always happy to make treatment decisions when the case goes to court.

It is not for the court to substitute its own views as to what may or may not be in the patient's best interests for the decision of the patient if of full age and capacity (*Law Hospital v. Lord Advocate* 1996 SLT 848 per Lord President Hope at 852F).

Although this is a Scots law case and has no real precedent in England and Wales, the point made is still relevant. If the patient has capacity, then in theory, the court would not become involved, as patient autonomy would take precedence. What is not clear is whether a statute that explicitly stated the patient's rights would give the public and doctors more confidence about decision-making and planning for future medical treatments.

Incapax Patients

When asked about treatment decision-making for *incapax* patients, the lawyers interviewed raised several issues. Two points dominated, both concerning the issue of consent: first, the problem of doctors overriding incapacitated patients' consent,

My understanding is that the doctors can take a view about the capacity of the patient and can override the patient's own right to consent by saying the person is not capable of giving consent and therefore they will go ahead with [the treatment] on the basis that it is a reasonable and necessary procedure. I would think it is certainly good practice (EL01).

Secondly, consultations with lawyers were made by families who were unsure of their rights to consent on their relative's behalf, sometimes merely for advice and to assuage their doubts or fears.

My experience is to be consulted by the relatives direct but we occasionally have relatives who will come to us to ask "is this right?" particularly when we're talking about people who are suffering from fairly advanced dementia, by and large, so there's a lot of angst around that (EL05).

Doctors who previously had not been aware of the law on consent regarding the incapax patient also made consultations. This lawyer, who specialises in medical law had strong links with the local hospitals and had carried out informal teaching sessions for healthcare professionals on, issues of consent to treatment. She related some anecdotal evidence from her own experience.

...relatives still think that they can make the decisions, especially the elderly relative of the old aunt or the old mother, and up until about a couple of years ago they [doctors] were still getting relatives to consent and it wasn't until ... I'd done a couple of talks on consent and said "this is not legal". But I've actually had doctors ... well, surgeons, ringing me up and saying "this is right. They can't consent, can they?"... I've even had them ringing to say they've had a 'pre-med' and they haven't consented. "What do I do now?" So it is getting through to them but up until about a couple of years ago, they were still allowing relatives to consent (EL02).

These three interviews are examples of a misunderstanding among some doctors and the public on what the law on consent and *incapax* patients is. Doctors' lack of knowledge in this area compounds the public's confusion and in some cases probably causes discontent among family members.

In the present legal situation, there are no definitive rules by which to determine how medical decisions can be made in the case of a dispute. There may be several different methods of conflict resolution set up in hospitals, e.g. ethics committees, second opinion, mediation, etc., but the final decision would probably have to be made by the courts if all other attempts at a solution fails,

In cases of doubt as to the effect of a purported refusal of treatment, where failure to treat threatens the patient's life or to cause irreparable damage to his health, doctors and health authorities should not hesitate to apply to the courts for assistance (*In re T (Adult: Refusal of Treatment)* [Court of Appeal] [1993] Fam 95 *per* Lord Donaldson of Lynton M.R. at 116E).

Having to apply to the courts precludes a large part of society who will be unable or unwilling to take their conflict to court through lack of finances or lack of confidence in challenging the medical profession.

Refusal of Treatment

Lawyers were asked whether they believed that patients should be told, when they are being given treatment choices, that they could refuse treatment. The main response was from lawyers interviewed who answered in the affirmative. One lawyer gave a comprehensive explanation of why she thought that was the case.

Yes, absolutely, I think that's important. You see I know I can refuse and I could refuse, well, I know it now. Whether I would know it [or] whether I would be able to hold on to that knowing when I was in a situation where I was ill and there was an option for treatment, I don't know. Would I then think, "oh, I can refuse this", I'd hope I would, and be reminded of it by people around me "you don't have to do this", that's the important thing. But, yes, I think doctors should say to people "you don't have to go through with this. It is your choice whether you do it or not", and I don't think that happens and I see a lot of medical records and very, very rarely do I see that anywhere, written down or anyone ever says to me "well, he said I didn't need to go through with it and it was my choice ultimately". I think that's important, that's really important (EL06).

This lawyer's response points out the issues many people can have with refusing treatment. First of all, many people may not be aware of their right to refuse treatment even if their doctors disagree. The second point is that even when people do know they have the right to refuse, they may not remember this when they are in an ill situation. Whichever is the case, what matters is this lawyer, and possibly a great deal of other people, would be grateful of being reminded of this right at the time when it matters. Patients' autonomy can be reinforced through giving them the full range of options to choose from even if in conflict with the patients' "best interests", instead of acting paternalistically and restricting the choices given to patients to only those which the doctor thinks are appropriate.

Advance Directives

Legal status

Several lawyers interviewed were unable to decide whether advance directives were legally binding on doctors under English Law. One said,

I'd take a stab at saying that I don't think they would be legally binding but that they would be an expression of a wish, an intention and to that extent, they would have some weight. ... I don't know, but I don't think they could be any guarantee that this is what is going to happen to you. I've no idea. Do you know? (EL01)

Another would not advise a doctor that they would be binding on his or her decisions.

Oh, I don't think it's totally binding, absolutely not any certainty about it being binding but ... if the doctor's concerned about the patient you'd say, "what did this patient want?" Of course you've got the problem of when they made the living will and if the circumstances now are different. Now, I would say if a doctor came for advice and said he wouldn't do it, I'd say "you're not bound by it". I don't think, in law, you are bound by it (EL10).

The common law in England states that doctors are not entitled to act if it is known that the patient, provided he or she was of sound mind and full capacity, has made it known that he or she does not consent to certain treatments. To this extent an advance indication of the wishes of a patient of full capacity and sound mind are effective (*Re AK* [2001], per Hughes J. at 191) and these lawyers' uncertainty could lead to them giving doctors erroneous legal advice.

Due to the lack of experience in drafting and the difficulties in interpretation and even possible misinterpretation of such documents, many English lawyers who were interviewed felt that advance directives should only be considered and taken into account by doctors and other health care workers, but not automatically implemented.

To spell out in no uncertain terms that doctors are duty bound to follow, to the letter, an advance refusal of treatment is wrong. The law firmly and rightly holds that those who have undertaken to provide treatment or nourishment are not absolved from their duty by the patient's adamant

refusal, if that refusal is either incompetent or unlawful. However, if the circumstances agree, they do have legal status at common law and should be followed (EL07).

The point made above is an important one, regardless of whether the lawyers interviewed believed that doctors should or should not be bound by advance directives. A document refusing treatment must be valid and applicable before it can release a doctor from his or her duty of care towards the patients (see Lord Donaldson's four criteria in *Re T*, [1992]), otherwise the advance directive could be overruled and the doctor or hospital would not be held liable for assault for not respecting that refusal. However, if the advance directive were valid then the common law states that it should be followed and to ignore it means that the doctor and the hospital would be acting without consent. This situation was illustrated in a recent case of a woman, paralysed and only able to breathe with the assistance of a ventilator, whose refusal of treatment was denied by her doctors and the hospital trust, by claiming that she was incompetent (*Re B* [2002]). When it was verified that she was competent to make her own treatment decisions, she made a living will and still her refusal to consent to treatment was ignored. The court held that the hospital had acted unlawfully by continuing treatment against her expressed (oral or written) wishes. Dame Butler-Sloss stated in her judgement,

the [hospital] trust had been under a duty to do something effective to resolve the dilemma and to do so with some degree of urgency ... There is a serious danger, exemplified in this case, of a benevolent paternalism which does not embrace recognition of the personal autonomy of the severely disabled patient ... The failure to do so has led me to the conclusion that I should mark my finding that the claimant has been treated unlawfully by the NHS hospital trust by a small award of damages (*Re B (adult: refusal of medical treatment)* [2002] EWHC 429 (Fam), [2002] 2 All ER 449, [2002] 1 FLR 1090, [2002] 2 FCR 1, 65 BMLR 149 per Butler-Sloss, P at paras 92-99).

It could be argued that a statutory framework would introduce a welcome degree of certainty to the law in this area. It could provide a doctor with statutory immunity from civil or criminal liability if he or she withheld treatment either in accordance with a living will or upon the instructions of an attorney. Legislation could also contain safeguards regarding the witnessing and storing of advance directives which

could help to ensure that they are actually signed by the patient and are not granted as a result of undue influence.

It was not only the vagueness and lack of clarity surrounding living wills that put off some lawyers. One believed that making advance directives legally binding would put doctors in an impossible position, for example,

I do not think that living wills are actually legally binding in England. Firstly, it is possible for a person to request in a living will a treatment, which it would be legally impossible for the doctor concerned to administer and the doctor concerned could not be legally bound to carry out such a request despite the terms of the advance directive. Obiter dicta in Bland suggest that it may be possible to make an advance directive which is legally binding. As far as I am aware, however, the status of living wills is that they remain merely expressions of the granter's wishes although they may be highly persuasive and may be upheld by the courts (EL04).

The above situation would only apply, if a person were allowed to make “positive” advance directives, in other words, to state that he or she wanted a certain treatment, rather than to only specify the treatments that are not wanted. These “positive directives” are seldom used as people more often use advance directives to ensure that they do not receive treatment. Demands for futile treatments could be discouraged or even prohibited if a statute existed to give clearer guidance on the purpose of advance directives.

The following lawyer believed that negative advance directives would be binding, but there still would be the problems of obscurity in their drafting.

They are in the negative sense, in that if it is a refusal of consent then yes, they are binding. I think it would be an offence to go against a clear statement, but of course, what is a clear statement? It doesn't really strike me that there are going to be many circumstances where you could make such a clear statement, when you've faculties. But ... cancer patients are the most obvious, but generally, I would have thought it's difficult to draft something that is in fact legally binding (EL03).

From a jurisprudential point of view, one lawyer was aware of the differences that could exist between the law in theory and in practice.

I think there's probably a difference between extrapolating from the case law, what the law ought to be and what the law actually is. I think even if you look at medical practice, if you look at some of the guidance that's come out in England from the GMC about doctors' positions on advance directives ... it seems to be much harder than what I actually think doctors would do (EL06).

Finally, one lawyer preferred the BMA Code of Practice (1995a) on advance statements to statutory provision, and argued that the courts, through the common law, were able to fill in any gaps. In other words, he did not espouse the need for statutory backing to strengthen the legal status of advance directives.

I think that some of the perceived advantages of a legislative framework could be achieved more flexibly by a code of practice. The courts in the UK have been able to address the issues of civil and criminal liability arising from medical treatment of incapax patients effectively in the absence of governing legislation and I feel that any cases that arise can be adequately and, arguably, more appropriately disposed of at common law (EL05).

In theory, this solution would be satisfactory, but in practice, because the Code is written by a professional organisation, is only voluntary; doctors are not compelled to adhere to it. Some doctors interviewed did not even know that the code existed and many others regarded it as only a guide to best practice.

Conflicts

Conflicts arising between doctor, patient and relatives can reach the point where legal advice is required. One lawyer spoke of conflicts between doctors and relatives over disagreements about treatment, mostly in the area of treatment withdrawal. Usually the relatives contacted the lawyers interviewed because they disagreed with the doctor's decision to stop treatment, and a communication from a lawyer often stopped events progressing. However, according to one lawyer, the main reason conflicts arise is that information is being withheld from the family and that an element of concealment naturally exists within the culture of medicine,

Sometimes [we send] a letter saying, "We understand you're going to withdraw treatment. What's the basis?" and they back off ... sometimes we can engineer a meeting to resolve this, but even then, there is still a problem with secrecy in the NHS. Relatives do feel that things are going on which they don't know about (EL03).

The secrecy mentioned by the last lawyer may be part of the overall imbalance of power that can exist between doctors and patients. The corollary of this can be a feeling of disempowerment by relatives and patients; in particular, a lack of knowledge or lack of understanding of the situation can be further disempowering.

There is an element of [disempowerment] I think because of the way things are presented. The expectations of the NHS are very high, that this patient is going to be made well again and therefore everything must be done to achieve that end. There's sometimes a complete lack of understanding that, no, that's not going to happen ... but there's still this requirement on the part of relatives, well, all this treatment should be given. Cost is irrelevant (EL03).

One conclusion that might be drawn from this statement is that patients are disempowered because the healthcare team and the relatives believe that the patient must be made well at all costs. A more realistic perspective is that it is impossible to make everyone who is admitted to hospital well; in fact many people who are admitted to hospital never recover from their illness. The disempowerment felt by patients may be through well-intentioned acts, but it can be argued that regardless of the intentions, medical paternalism erodes individual autonomy and ultimately disempowers people by ignoring their wishes.

Overriding Advance Directives

Generally speaking, English lawyers, whatever their views on the legality of advance directives, consider that the decision to override such a directive should not be taken lightly. One lawyer recommended that he would advise doctors that to consider the reasons to override carefully and not just to act in a way that reflected their personal choice.

You would have to show good reasons for not accepting what it says. I think you would be foolish to ignore it just because you want to ignore it but to look at it and say, "well, it's not a sensible way of going ahead with this patient. I accept that this patient thought that it would be at that time but I'm going to ignore it for the following reasons" ... and then I think ... you're not acting illegally" (EL01).

Another lawyer felt that a conscientious objection to advance directives in principle would not be a good enough reason to override them. The doctor should instead refer the patient to another consultant, in the same way as for the termination of pregnancy.

I think, in the same way that doctors have to remove themselves from the situation if they don't agree with terminations, they ought to remove themselves from that situation (EL01).

Referral to another consultant was seen to be very important, but one lawyer went so far as to suggest that the doctor might be in the wrong profession.

... I think they'd have to question what they were doing in terms of working in that field and if it's the field, for example, strokes or spinal injuries or something like this, if they have a conscientious objection to it ... (EL07).

Doctors might find themselves facing a civil court action if they did not have a very good reason for treating a patient against the wishes expressed in his or her advance directive. Some lawyers interviewed were interested in discussing whether doctors who ignored advance directives could face some sort of legal sanction. The criminal law was even mentioned as being an effective method of expressing society's displeasure at doctors who ignore patients' wishes.

Well it is an assault. It is an assault and battery but there are civil methods of dealing with assault and battery. It's also a tort. The thing about it being a criminal matter is that I think it emphasises its importance and the importance that society gives to it and so I think that would really be one of those things where you'd have to have some kind of public debate about it, to work out whether that is something that seemed to be sufficiently important to us as a society to merit criminal punishment rather than civil. I don't know the answer really, but certainly it would give it much more importance than if it was just a civil [remedy]... (EL06).

While none of the lawyers interviewed would go so far as to want doctors who ignored a valid advance directive charged with a criminal offence, several agreed with the above statement.

Patient Autonomy and Balance of Rights

Very few English lawyers, who were interviewed, had experience of drafting or interpreting of living wills but some did have opinions on how advance directive might safeguard patient autonomy. One commented,

I think they could be a way of protecting autonomy, but, again, it's the nature of the advance directive, it's very much what's in the content. I think, in this country, we live our life, not expecting things to happen so we think there's no problem. People may develop a certain disease process, they then make a directive, with regard to that disease process, and it may be very specific to that (EL05).

This would seem to be both a good time and a good reason to make an advance directive. According to another lawyer, patient autonomy may be enhanced using advance directives, but only,

... if they're made with knowledge. I think that has to be the key because if someone just came in through the door and clearly hadn't discussed something I wouldn't see how that would improve their position, their autonomy at all. I think I would send them away and say "look, go and see your GP and then go and see your consultant and/or his registrar and get a full explanation of what your condition is, what the options are, what the prognosis might be" and, at that point then, yes, a directive may enhance the patient's position but [until then] no, I can't see that it does (EL08).

The point being made here refers again to knowledge about what the person specifically wants to make clear in the advance directive. More importantly, the lawyer is concerned that there is communication between the person making the advance directive and the doctors involved; a significant and recurring theme. Another lawyer who had much stronger views on patient autonomy again addressed the information issue. He believed that autonomy must hinge on information and that often patients do not have adequate information on which to protect their personal autonomy. Information mainly will come from the medical professionals who control the type and amount of information given to the patient. This may result in a feeling of disempowerment by the patient to make more informed decisions.

If I can't avoid it then I have to go in knowing that actually I have very little autonomy because I am in a very ignorant position when it comes to what is happening with my body. It all depends on what a doctor chooses to tell me.

I may not know the questions to ask to find out the information. They may not choose to give me the information and so even when I consent to something or agree to something, it's done on the basis of the information that I am given, which is often just not sufficient. So I'd have very little autonomy when it comes to my body in a hospital and I accept that is the case. Unfortunately that's it, so in the same way, if it came to the situation where I was lacking capacity, my autonomy [would have] gone anyway really, that's it. That sounds very negative and pessimistic but that's it (EL10).

The point being expressed here is that even powerful, professional people such as lawyers, become disempowered by the vulnerability of being ill. The upshot is that individual autonomy is very difficult to hold onto in these situations and advance directives may or may not be enough to balance the disempowerment felt by patients on entering hospital.

Living wills, or advance directives may also help to protect patients' human rights, in particular, the right of protection from cruel and inhuman treatment. The *Bland* case was given as an example of cruel and inhumane treatment. A young man, suffering from a persistent vegetative state (PVS), with no chance of recovery, was tube fed for several years before his parents approached the courts to allow doctors to stop artificial nutrition and hydration (*Airedale NHS Trust v. Bland* [1993]). Most lawyers disagreed that giving a patient all appropriate medical care could be judged to be cruel and inhumane treatment and considered that it would be unnecessary for an advance directive to be required as protection against infringement of this human right. However, one lawyer had more to say on the subject,

... doesn't that have to be allied to the outcome? You may be very seriously ill and you may need tube feeding but ultimately the prognosis is that you will recover, fingers crossed, and therefore it's a perfectly reasonable thing to do and, if you knew that, you would say "yes, do it. I want to get better." So ... I'm just not sure how an advance directive would work in that sort of situation because ... a lot of it does come down to these sort of disease cases, the progressive disease cases. I can see, when you think it through, what is being implied behind that and then yes, can understand that if someone said, "I do not wish to be tube fed. If I reach that point I simply wish to be given pain relief and that's it", then that would be found appropriate for them to do (EL08).

Finally one lawyer commented that sometimes a person's autonomy could be protected, but at a price,

Treatment decisions that respect and enhance the autonomy of the patient may at the same time disregard and shatter the autonomy of the patient's caregivers and the rest of her family (EL07).

This final comment adds an extra dimension – the autonomy of the family - however, as relatives have no legal rights in treatment consent issues, it follows that their opinions carry no weight. On the other hand, the doctors' duty to make treatment decisions in the patients' best interests and the patient's autonomy may clash and this is where conflicts can develop.

Doctors

All interviews with doctors were carried out face-to-face except three, which were conducted by telephone. The interviews pursued two major themes: treatment decision-making and how advance directives are involved in decision-making. The doctors interviewed specialised in three areas: care of the elderly, neurology, and oncology. All interviews with doctors were tape recorded and transcribed before analysis.

Treatment Decisions

Capax Patients

Engaging and informing patients is at the heart of good clinical practice. The General Medical Council's guidance on good medical practice (GMC, 2001) makes clear that listening to and respecting the views of patients, giving them information in a way they can understand and respecting their right to be fully involved in decisions about their care, represent the ethical bedrock of good clinical practice. This good practice advice is relevant to the whole of the medical profession across the UK.

Elderly

Decision-making for cognitively-aware elderly people who have capacity is a significant matter for healthcare professionals. One Professor of Geriatric Medicine

believed that it might be prudent to restrict the number of options for the person to choose from,

I personally have come to realise that it is very important to get across to our younger colleagues that you don't necessarily present all the possible options to an individual because some options are sometimes not realistic. I notice that people talk about autonomy but they sort of say "well, we could put you on the ITU [Intensive Therapy Unit] but we don't really think that's an option for you". I mean that's the subtext of it. As if to say, "Well, you don't really want to go through all that, do you?" (ED01).

This is an example of Lukes' (1974) third dimension of power, which states that by restricting the available choices, the doctor exerts power over the patient by controlling his or her worldview of the available choices. This particular doctor felt it better to a more matter-of-fact approach by saying,

"These are the options, this is what we have in mind for you, these are the risks, these are the possible benefits. Do you feel that you want us to proceed?" And I, personally, feel that you actually should give people a chance to think about it, if there's at all any time, and consult with relatives (ED01).

The doctor is doing all the right things – giving the patient the opportunity to consent to or refuse treatment and by giving time to consider the options. Nonetheless, the doctor who is the most powerful party in the relationship is still controlling the options available.

Neurology

For all patients in England and Wales (and in the Netherlands and Scotland), medical treatment requires the informed consent of the patient. The person giving the treatment, usually, a medical practitioner, must explain the reasons for the treatment, and what treatment is recommended. In most cases, the treatment does not require signed consent but it does still require explanation. The cases where doctors prefer the patients' written consent tend to be more formal and may involve procedures, which have significant associated risks, e.g. surgery, general anaesthetics.

We would get the form signed either by the patient or quite often by a member of the family just to witness that we have explained the potential risks and benefits, for instance if we were giving clot-busting treatment, or

thrombolysis, for patients with acute stroke, which we don't do very often (ED05).

A problem may arise with stroke patients because, in many cases, communication may be impaired even though a general cognitive function is not. This may lead to a communication problem, where the doctor can communicate the issues to a patient, and the patient may be able to process them perfectly well but is unable to communicate his or her consent. In this situation it is difficult to know how the doctor can tell if the patient has given his or her consent. Having the form signed by a family member is inconsequential, as the family member cannot consent on the patient's behalf. Getting the patient to sign may be the only way that the doctor can verify his or her consent. Refusing to sign would be an obvious option for the patient and a clear sign to the doctor not to start treatment.

Oncology

Similarly, oncologists felt patients should not and ideally would not be rushed into making a quick decision unless this is absolutely necessary.

Most of the decisions can be delayed for 24 hours for the person to really start thinking about and internalising what you've put to them. If there's urgency, then obviously different things could get into gear. I think it's also important to say to the patient that if they find it too difficult to make the decision that you would be prepared to make the decision on their behalf (ED07).

This particular doctor might be prepared to make the treatment decision for the patient, but the patient was still able to be consulted, and therefore the decision was being made on the basis of substituted-judgement, as recommended in the GMC guidance on good medical practice (*supra cit.*). Nevertheless, if the patient has capacity it is unnecessary for the doctor to make the decision and the patient has capacity, then he or she must consent or refuse on his or her own behalf. This particular doctor continued to describe why patients might abdicate their autonomy to their doctors.

You know, taking into consideration what they say, but to add "look I'll shoulder this burden", and I quite often have patients ... probably 1 in 8 patients, would say to me, in response to that kind of offer, "I really find this very, very difficult and I have confidence in you and I'd like you to make the

decision". In which case I thank them for their confidence and say that I would exercise that investment of confidence in their best interest in discussion with the rest of the team and that I wouldn't hesitate to consult with other consultants if necessary. So that's how I respond to that (ED07).

Confidence in one's doctor to act according to one's best interests is a happy situation to be in, but these patients are also abdicating their autonomy to the doctor. What is interesting in these instances is discovering why patients are happy to relinquish their autonomy to their medical practitioners. It may be because it is easier to allow the doctor to make all the decisions, rather than challenge the choices and decisions put forward by the doctor; it might be a position of individual autonomy bowing to professional autonomy in case of "doctor knows best".

Incapax Patients

The law on consent to treatment for *incapax* patients in England and Wales is similar to the situation in Scotland before the enactment of the Adults with Incapacity (Scotland) Act 2000. The doctor has the ultimate decision-making authority, and no one can actually consent or refuse treatment on another adult's behalf (*In re F (Mental Patient: Sterilisation)* [1990] 2 AC 1³²). This should change with the passing of the Mental Capacity Bill, which was discussed earlier in this chapter. While many doctors interviewed would consult with families and friends to determine the most appropriate course of action, all the doctors interviewed were aware that they have at some stage to say to relatives without causing offence, that in terms of the law they have no decision-making authority for other adults. As no adult or court can decide for another adult, the best that can be done is to garner information before making a decision.

Elderly

The approaches of all the doctors interviewed did not differ greatly. In elderly care, one doctor practised substituted judgement and explained his approach,

I think generally the physician's approach ought to be that one needs to try to determine what the person's wishes would have been if they were able to participate in the decision and that could entail gathering information from

³² The court held that even the court itself does not have any *parens patriae* or any other jurisdiction over the person of an incompetent adult.

relatives, saying have they ever expressed a view about active management given this circumstance (ED03)?

In care of the elderly, decisions are often related to whether to give or withhold certain medical treatments, for example, antibiotics in persistent chest infections, or some major surgical interventions. Most doctors interviewed would approach this by detailing the prognosis and the probabilities of certain events happening to the relatives. One doctor related how he would proceed,

I think one needs to sketch the prognosis to relatives and say "given this", and we're talking about a person who's going to be dependent, with invasion of their privacy, probably quite a lot of loss of amenities of life, "has she or he said in the past that they would prefer not to be treated?" I think that it's terribly important to emphasise to the relatives that one isn't asking them for their view but asking what they think the person's view would have been (ED02).

His continued explanation of how problems might be solved shows experience of developing a technique that manages to remain within the law while showing sensitivity to the family at such a difficult time. From his answer, it is unclear whether this doctor was aware that relatives and family of *incapax* patients have no legal right to make treatment decisions on their behalf, but it was still important for the doctor to include them in the decision-making process. This dealt with two important, but tangential parts of decision-making: the need to involve the whole person, which would include family members, and getting as much information on the patient's views and wishes in order to make a proper and considered judgement of what the patient would want done in the circumstances.

I've developed different techniques of actually making sure that the relatives are distanced from the burden of responsibility because quite often they just can't decide. They say "I can't make this decision", so you have to say, "well, I'm not asking you. All I'm asking is for the facts"... and I try to stimulate memory ...I also ask about their general view about medical interventions, issues about privacy and dependency and so on. So if you actually unpack it, you sometimes get strands of recollection that come up, I don't think you can just fire a blank question. That interview itself usually takes about 20 minutes to be quite sure that they do or they don't know what the relative thinks (ED02).

As the doctor continues, it becomes clear that the doctor is aware that relatives do not have the right to consent. He employs substituted judgement by using the family's knowledge of the patient to find out what he or she would have wanted under the circumstance and therefore deciding on the most appropriate treatment for the patient at that time.

Neurology

In neurology, doctors interviewed said that decision-making for incapacitated patients may present problems, particularly in stroke medicine where the patient has a degree of brain damage because of the stroke. This damage may or may not involve any intellectual impairment or it may involve only a difficulty in communication through both physical and intellectual disabilities. For one physician, certain treatment decision-making may not require high levels of capacity and some choices can be communicated even if the patient's competency is quite low. He went to explain,

When you put a nasogastric tube down to feed a patient, s/he often pulls it out and we have to decide whether they are systematically saying "look, I don't want treatment" even though they're aphasic or somewhat confused, or whether they're just picking at their nose and pulling at this thing without really intending to do anything along those lines. Sometimes with our patients who have a sensory loss for the left side and don't recognise that side, they find this tube and they don't see it as being relevant to them and they pull it out. So that's a typical scenario that we have in stroke and we have to try to decide, well, what is going on here? Are they philosophically saying to us, "we don't want to be treated?" or is it just by accident that they've pulled out the tube? (ED06)

This explanation shows a problem that the doctor may be faced with: the patient may or may not object to the treatment, and may only be reacting to, what he or she thinks is, an alien object and trying to get rid of it. Nevertheless, the patient may be definitely objecting to the treatment. It is difficult to see how the doctor could differentiate between the two positions. Without any prior discussion with the patient or any indication in written form (advance directive or similar) the doctor has only two options – to rely on information from the relatives and to make an educated guess at what the patient wants; neither of these options appear to be satisfactory under the circumstances.

Oncology

The oncologists who were interviewed seemed to adopt a holistic attitude towards their patients, especially in the area of decision-making. Because of the nature of their disease, and because of the treatments used in the tertiary stages of cancer, there has often been a prior discussion between doctor and patient concerning future treatment, and what would happen if the patient becomes unable to consent to or refuse treatment. Respect for the patient's autonomy seemed to be treated seriously and in the words of one doctor,

In days gone by, I think doctors tended to take a rather paternalistic attitude, this idea of doctor knows best and certainly, I think since I've been qualified, there's been quite a rapid move away from that, so much so that there is a great deal of improved communication. So ideally the patients themselves [decide]. Just because they can't speak, there are other ways of communicating with them and that would be the first port of call. If that doesn't work, you're then reliant on relatives and friends and getting as much information from as many people that are close to the patient as is possible to really maximise the amount of information. You, as the practitioner, then have to try to understand what a patient's wishes would have been in the circumstances that they find themselves (ED05).

In the approach to decision-making for *incapax* patients, the doctors interviewed appeared to be moving away from using only the best interests of the patients as a model for making treatment decisions for incapacitated patients. There appeared to be a move towards trying to discover what the patients' wishes were before the events that caused their inability to make decisions. This was seen particularly in interviews with doctors in care of the elderly and oncology where there was effort to find out what the patient would have wanted. The exact method of decision-making used may differ within different specialities, but this may be because of the amount of time spent with patients before their incapacity and the relationships built between doctors and patients. The move towards substituted judgement and away from the pure best interests ethos is a step in the right direction towards recognising individual, patient autonomy as being equally valuable to professional autonomy, at least in the case of the English doctors interviewed.

Power

Elderly

Power, lack of power and patient empowerment are important aspects of the doctor-patient relationship. Clinicians were asked how they viewed the balance of power, between them and their patients: is it a case of “doctor knows best”? One doctor in care of the elderly agreed with this explanation,

Yes, it's that sort of power. It's the power of social position and it's the structure of society rather than a legal power, that's what we're talking about, yes, I think that's true. Things might change and I think things have changed over the years ... still I think with the majority of consultants and the majority of patients, the doctor decides and the patient fits in (ED01).

Neurology

One neurologist commented on the practical problems that arise in the doctor-patient relationship,

The constraints on a patients' power arise from a situation to agree with their doctor's advice and besides access to doctors of the patient's choice is limited. Patients often can't choose the doctor they want to see; can't get second or third opinions and will find it difficult to refuse the medical view, especially when they need a sick note for sick pay (ED06).

From the few comments made by the doctors interviewed, two problems arise for patients in relation to the power imbalance involved in the doctor-patient relationship. The first is the respect and reverence people give to the traditional position of the doctor within society, the second is more along logistical lines. The NHS does much to perpetuate the state of affairs where doctors have greater power than their patients. If patients cannot pick their specialists and cannot get a second medical opinion easily, then the patients often must take what they can get, unless they can afford private healthcare, where the power may be more evenly balanced.

Decision-making Models

Where people want to be involved in their treatment they may even wish to work in partnership with their clinicians. Public consultation shows that patients, or potential patients, would like to draw upon the,

essential knowledge, skills and experience of healthcare professionals, but they also want to be able to contribute their own knowledge about their condition and their own perspective on what matters most to them. They want the chance to reach shared decisions about their care and treatment (Department of Health, 2003: 38).

The desire to participate in shared decision-making is dependent on the models employed by doctors, below are the models used by the doctors interviewed.

Elderly

Doctors in care of the elderly interviewed did not use the substituted judgement model because of the reported lack of reliable persons with the authority to act for the patients. An example of the responses among clinicians was,

My understanding of the way to exercise it would be to have a person to act as an advocate for the patient, who would argue the case. We've, to my knowledge, never actually had that formally in any of the areas that I clinically work in (ED02).

This is a means of using substituted judgement, but a more informal way would be to ask relatives and friends what the patient would have wanted in these circumstances, which this doctor had mentioned earlier. He said that he would ask the family,

Has there been a neighbour or a friend who's been in this predicament and did she, at the time, say that she would hate to be in that position (ED07)?

This is a perfectly acceptable method of employing substituted judgment and need not require a more formal basis.

Neurology

In neurology doctors interviewed did not seem to adopt a deliberate or particular model of decision-making, for instance, the substituted judgement or the best interest model. However, further probing during one interview revealed that,

I think these are the principles that come up but they're probably not called by their posh name. I think in practice, we do make every effort to try to establish what the patient's wishes really were but it can be difficult and, I'm worried that we might get it wrong (ED05).

This doctor have touched on an area deserves further consideration. Doctors may use the best interests model because it is safer than trying make a decision based on what the patient might have wanted, especially if the doctor is so far removed from that patient's position (e.g. class status or gender issues) or if there are no friends or relatives to ask.

Another issue that was presented by an interviewee was the blurring of boundaries between medical treatment, which requires the patient's consent and other aspects of care such as artificial feeding and hydration, etc., which have been designated as medical treatments by the courts and by the BMA. The dilemmas of withholding and withdrawing these treatments were also factors that had to be considered in decision-making.

Oral feeding, I think, can't be regarded as medical, whereas peg feeding (PEG) must be ... and then there's another distinction between initiating and withdrawing treatment, I'm not clear that the law distinguishes in principle between them. I mean obviously there are practical issues and I think that in the case of ... well obviously things like the Tony Bland case where it's simply an issue of withdrawal of feeding, which ... in that case, I think, it had to be regarded as a medical treatment (ED06).

Oncology

Doctors in oncology who were interviewed said that treatment decision-making would often be arranged before the patients' incapacity; however, sometimes other peoples' perspectives interfered in the process. This was because the patient's relatives often believed they had a right to contribute to the decision on their relative's behalf. This was a problem that emerged in all three jurisdictions and a theme that will be dealt with in greater detail in Chapter Seven.

It is surprising how forceful relatives can be, saying, "we know what they would have wanted", or often "we know what they would not have wanted". Families often seem to support each other in this and once a few family members have spoken together, there's often a very firm view held by them, which is then presented to the doctor. Sometimes, occasionally they say, "well, we've no idea what they would have wanted, doctor, tell us what you think", but more often than not, the family say, "we think we can give you the view of what they would have wanted" (ED08).

From these statements, the doctors interviewed in England do try to find out what the patient might have chosen in the circumstances. They may not call it “substituted judgement” but it does appear that they are aware of the need to respect the patient’s autonomy. The problems cited by the interviewees: lack of legal authority to advocate for the patient; uncertainty of the decisions advocated for the patient; and the family’s insistence of knowing what the patient would or would not have wanted in the circumstances, bear out a need for some sort of relevant documentation of the patient’s wishes. Advance directives may fill this gap and provide the clinical team with information on which to base their decisions.

Right to Refuse Treatment

As in Scotland and the Netherlands, patients have the right to refuse medical treatment when admitted to hospital. Additionally, the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing jointly issued guidelines to outline legal and ethical standards for planning patient care and decision making in relation to cardiopulmonary resuscitation (BMA *et al*, 2001). The focus of the guidelines is situations in which decisions are made in advance and form part of the patient’s care plan. In emergency situations where no advance decision has been made are also covered. All the medical interviewees were asked if patients were explicitly informed of these rights.

Elderly

The geriatricians interviewed did not generally inform their patients of the right to refuse treatment. One also expressed doubt whether it was something that they should do in elderly care where people come in to hospital with huge fears anyway.

So they’ve come in with a urinary tract infection and the expectation is that they’re going to get better. I don’t think it’s fair to ask them to sign a form about “do not resuscitate status” (ED01).

Another doctor felt that, due to the nature of the patients who are admitted to a care of the elderly facility, it would be upsetting for them to be asked about their wishes in respect to resuscitation. This doctor also thought that talking to patients about

refusing treatment before the situation arose, when this conversation might be necessary, would confuse them,

I don't think it's appropriate to actually ask every patient "do you want to be resuscitated?" because, it's a very difficult conversation to have even at the best of times and to put somebody who's a bit confused and distressed and worried through that is not fair (ED03).

Neurology

One neurologist had an interesting perspective on the issue of whether to discuss treatment refusal with patients on admission, or early in their treatment regime,

I think it is likely to give a misleading impression that you're going to do something ... it sort of gives the impression that we're wanting to give the treatment for our benefit rather than theirs. I think patients should be given every opportunity to express their opinions and I think a good example of that is in nasogastric feeding where patients generally ... we don't sort of tie them down to put the tube down their nose, if they really don't want it, they will fight it off. If it's just an unpleasant procedure then they may be able to calm down until it is done (ED06).

This approach places the onus on the patient to reject forcefully a procedure by "fighting off" the healthcare professional. If the patients are unaware of their right to simply refuse, by saying "no thanks", they may end up suffering in silence and undergoing procedures or treatments that they do not want. Neurologists also commented on the resuscitation question.

I think the situation of CPR [cardio-pulmonary resuscitation] is a particular case in the sense that there's no time to take decisions and involve the patient at that time, nor is anybody else at that time. So it has to be decided in advance. But I think the impression is given and I think the medical profession is almost entirely responsible for this, that in terms of the wording of the DNR "do not resuscitate", it gives a clear impression that we could save your life if we wanted to. Whereas in fact, in 95% of the cases, it doesn't matter a damn what we decide to do because we're not going to save you even if we tried. The futile attempts at resuscitation are just that ... and I think that most decisions should be purely medical because you know a lot of situations where cardiac arrest is likely to occur ... which would almost preclude any successful resuscitation. So I think it's very difficult to give such emotionally loaded information either to patients or families in a way that allows them to express their belief freely. And that's why I think that advance directives, I hope, could make a big difference (ED05).

Oncology

Patients receiving treatment for cancer were not told of their right to refuse treatment by the oncologists interviewed,

Not by me, probably not by my team. I don't know whether part of the nursing/admission process would address that issue. I suspect, in general terms, the answer is "no" (ED07).

These doctors raise two conflicting points, first, patients need to be asked about CPR in advance because there would be no opportunity to ask when it was required; therefore it is correct that this question is asked on admission. Second, by asking about CPR, the doctor implied that it would be successful, which is wrong in the majority of cases. In this respect, this doctor thought that this was a medical judgement and that the question about CPR was therefore inappropriate. A third point that results from this discussion is the difference between asking about CPR and reminding the patient that he or she has the right to refuse treatment at any time. Unfortunately these two issues seem to get mixed up and this may be a reason behind doctors omitting to tell patients of this right. However, even if a doctor does not think it appropriate to ask if a patient wants CPR, the reasons behind this are unlikely to be the same as reasons to avoid telling them of their right to refuse treatment. Nevertheless, no reasonable explanation was given for withholding this information from patients, apart from wanting to prevent further anxiety.

Conflicts in Decision-making

Elderly

A doctor in care of the elderly described an interesting conflict that arose when a member of the clinical team disagreed with the rest of the group and took on the role of patient's advocate,

Whereas the rest of the team said "we must withdraw treatment", one of the consultants actually saw themselves as the advocate but never declared that and so it went on for months and caused divisions in the team and ultimately after some other events, this particular consultant said "well I was just being the devil's advocate", which is an unfortunate turn of phrase but ... he was an innocent advocate. You might say that was very destructive. I think there could be a role and I think this is possibly a model that we should move towards for the patient advocacy model but I think, on the whole ... almost

without exception, we try to come to a balanced assessment as a team as to what we think is in the patient's best interest. There's not really adversarial kind of argument, it's a consensus process (ED02).

This unusual situation shows how conflicts may arise when one person disagrees with the treatment plan.

Neurology

Neurologists interviewed referred to conflicts with relatives and how they might be resolved. One doctor explained how he would try to satisfy the relatives' needs to be involved with the most appropriate treatment for the patient,

I will consult relatives and try to involve them in the decision but make it clear that it's my decision or it's our decision and if it is clear that the relative has very strong views, then yes, I am very reluctant to go against them unless I feel that it's directly against the interests of the patient. If it's going to cause long or futile suffering, then I'll do something and be very blunt about it. And if we can't reach agreement, then ... it could conceivably come to the patient being moved elsewhere or put under the care of another doctor who feels differently about it. I've never had to do that (ED05).

Another neurologist described a case where a conflict arose due to poor communication among professionals and between professionals and relatives:

There was another case recently, where a man who'd been under my care had had a stroke, two heart attacks and a life threatening haemorrhage all in the space of about 10 days and it was a very difficult situation to manage clinically. After one of the heart attacks he was admitted to another ward and obviously there'd been some discussions about his resuscitation status, which I felt weren't conducted in the light of full knowledge of the clinical situation. None of my team was involved and the situation where resuscitation is most likely to be successful with a good long-term outcome is in the first 24 hours after a heart attack. We discussed it with the family and the message that came back to me, indirectly, was that the patient himself had expressed a strong wish not to be resuscitated. The patient was, I think, given morphine and by the end of the morning the [family] were able to discuss it with me but I was suspicious about this because there hadn't been any hint of this previously and in fact I actually wrote in the notes that if these were the patient's wishes, we must respect them but there was a reasonable possibility that cardio-pulmonary resuscitation in the early stages might have been successful. In fact this chap did have a cardiac arrest and died a few hours later. I think there was a split amongst the family, I don't think his wife agreed that he'd not want to be resuscitated but unfortunately the message

that came back to us from other members of the family was that those were his wishes. One of the biggest problems is simply communication (ED04).

Again, the problem of lack of communication and lack of knowledge or consensus of what the patient wants can cause ill feeling and conflicts within the family and between relatives and medical practitioners.

Oncology

The oncologists were asked a similar set of questions about a situation where there is a disagreement between the clinician's opinion of the best course of treatment, and what the relatives think, with very little indication of what the patient would have wanted. They were also asked how this might be resolved.

In general terms, we err now on the side of going along with the patient's relatives, even if there is an area of disagreement, you would try to sensitively explain your own point and probably ... it's a bit difficult to generalise but probably you would say my feeling would be based on past experience of patients in similar situations and you'd probably remind them that they've never been in that situation before. But all the same, it would be very unusual to overrule patient's relatives' wishes if they were really robust about wanting one thing or another (ED07).

These doctors interviewed could be wrong in going along with the relatives if their wishes conflicted with any known wishes of the patient or if their wishes were in conflict with the doctor's best judgement. These cases might have produced less conflict and saved time if the patients had executed advance directives laying out their medical treatment wishes.

Advance Directives

As with the Netherlands and Scotland, doctors in England had little experience of dealing with patients who had advance directives. To establish their knowledge of these documents, doctors were asked how they would define an advance directive.

Definitions

Elderly

A consultant working with the elderly had previously taken part in discussions with colleagues on the definition of a living will.

We made a decision about the terminology ... What you can say, strictly speaking, is an advance refusal of treatment is not an advance demand that no one does this or that, which they can't do; it's really an advanced refusal (ED01).

Neurology

The neurologists interviewed agreed that an advance directive would be written by a person who is of sound mental capacity, and would contain 'a freely expressed decision, which spells out all sorts of treatment or medical interventions that they are willing or unwilling to subject themselves to in the future' (ED06).

One neurologist discussed the need for certain treatment and procedures to be detailed in the document. He explained that because one particular treatment or procedure was rejected, it could not be assumed that all others would also be refused,

I think one of the major issues about DNR [Do Not Resuscitate] orders, as they're used at the moment, is that they're confused with withdrawal of treatment. There's a whole world of difference really. If I had a serious illness and felt that the chances of successful resuscitation were not good, then I certainly wouldn't want people jumping on my chest at the moment of my death, but I certainly wouldn't want that confused with unwillingness to undergo every other kind of treatment and it is often confused and people are mentally written off. They say, "Oh, he's not for resuscitation". It means that they don't bother to treat his pneumonia or whatever it is and I think that can be a major human rights issue actually. In a legal document, I don't think if you're saying that "I do not want to have CPR" or "I don't want to have tube feeding if I'm permanently incapacitated and unable to swallow" that you would be refusing other kinds of treatment. ... I think any doctor or professional that took it to mean that and therefore didn't give those sorts of treatment, would be on extremely dodgy ground and so I'm not sure whether it's necessary in principle or in practice to list the things that you are willing to subject yourself to. Yes, it's options, which you could tick, on the form if you like. But I think giving a whole list of things, which you would want to have, is unnecessary and impractical (ED05).

To detail all aspects of care to be refused would mean that the document would be overlong and complex. It would have to represent a definitive list of procedures for

any possible medical condition – an impossible task. Unfortunately none of the jurisdictions has specified any particular form of words or design of document and it is left up to persons executing the directives to take legal and medical advice as they see fit in making their wishes known in advance directives or living wills. Help and advice can be obtained from lawyers, governments and various organisations along with examples of documents and pro formas.³³

Oncology

In oncology there was a consensus of opinion on the definition of an advance directive. An example of this is given below,

It's a bit like a written Will, [in that] it was something to be done after your death, whether it is a video or a tape recording, just something that was documented to say that "this is what I want to happen". It can be updated any time, the same as a written Will with a solicitor really. It's just something that you can write down, someone's witnessed it and that's it and you would expect that your wishes would be fulfilled (ED10).

This is a very simple description of an advance directive but it does not take any of the problems that may be encountered in drafting such a document into consideration. To be fair, if doctors have had little experience of treating patients with advance directives, they will not be aware of the difficulties and advantages that these documents can have for doctor, patients and relatives

Use of Advance Directives

As was the case in the Netherlands and Scotland, few doctors in England and Wales have experience of patients with advance directives. Estimations of their use among patients of the doctors interviewed are illustrated in Table 6.1.

³³ Examples can be found in Appendix D.

6.1 English doctors' experience in dealing with patients with advance directives

<i>SPECIALTY</i>	<i>ESTIMATED PATIENTS WITH ADVANCE DIRECTIVES</i>
Care of the Elderly	< 5%
Neurology	< 2%
Oncology	~ 7% (mainly oral directives)

(Source: interviews with English doctors)

Elderly

One of the geriatricians interviewed had had little experience of patients with any type of advance directives. He believed that there may be more in the future, however, and to be taken seriously, they would require to be made well before their use.

I think these are so few and far between at the moment, it's usually very clear-thinking individuals who think about the benefits of an advance directive like this to them and make it many, many years before the relevant time comes and I think those are the ones that I would find persuasive (ED02).

This doctor makes an interesting point, as many more doctors would argue quite the opposite. The problem many have with advance directives made well in the past is that they become out of date for many reasons, for example, advances in medical technology and treatments. The BMA, in guidance to doctors on consent and refusal of treatment added this caveat, '[i]ndividuals should also be aware that circumstances and medical science may develop in unforeseen ways in the interval before their advance statement becomes operative' (BMA, 1995b: Chapter 10). A change in the person's attitude to illness and disability is another example that might make the living will invalid or at least less relevant to the person's wishes.

Neurology

A neurologist who had seen few living wills commented on an unexpected explanation of why few people in his specialty made use of advance directives

I think very little, very few. I would be surprised if it's even 2% or something. Maybe other people have a different spectrum but the cases that I see; it's a very, very infrequent event. I have to say that the northeast is obviously also economically and socially deprived and so people don't really have that

awareness of expectation. The other thing to be said about the northeast, which I think is wonderful, is that there is a very, very well established tradition on the extended family. I mean the numbers of cases that we have that have no brothers and sisters or anybody else but a niece comes in and takes primary responsibility or a cousin comes up from somewhere else. That's the closest relative and will resume responsibility. So perhaps ... a topical or sociological question for research is whether, if there's a strong family network, is there really a place for a living will (ED05)?

For this doctor, advance directives are needed more where the patient has no close friends or relatives to advise the doctor of the patient's wishes. The doctor's response may show an over-simplistic view of family issues and ignores the possibilities of conflicts or ulterior motives between family members. It also ignores the fact that relatives have no legal authority over treatment decision-making.

Oncology

Finally an oncologist spoke of her personal experiences with advance directives.

Not at work, but I did on a personal level because my mother collapsed nearly five years ago with a massive CVA [cardio-vascular accident, more commonly known as "stroke"] and was taken into hospital. She always said to me that if it ever happened, she didn't want to be brought back, she didn't want to be a vegetable, she would have hated it. So when I went into the hospital to see her, she was on all these machines and I said "I know I can't tell you what to do because I have got no rights over this but this is what she told me. She doesn't want to be brought back. She doesn't want to be a vegetable. If there is nothing there, after the CT [Computed Tomography Imaging] scan, just take everything off her and she'll take her chances" and that's exactly what happened. The doctor agreed and said, "there is nothing there. She'll never come out of this." And I said 'right, that's it. Just don't do anything to help her and if she goes again, just let her go because she would hate it.' So, on a personal level, although I had no rights, she had made it clear to me exactly what she wanted, although she'd never written it down, and I just said to the doctor "this is what she said to me" and they would have to take that on board. But as it happened, they did and went along with it (ED10).

This is a case of an expression of the patient's wishes being taken seriously and followed by the doctor in charge. It therefore might probably be assumed that this doctor would also have followed a written advance directive.

Hospital Admission

According to the medical interviewees, it is not a routine procedure in England and Wales to ask patients on their admission to hospital whether they have an advance directive. Opinions varied, but a doctor in care of the elderly felt that while they were not currently being asked, *"I think we should be asking that. I frankly don't know whether it's in the nursing process yet but it should be"* (ED01).

In neurology opinion was ambivalent,

Not routinely, no. I think it will come in, as I say, I don't think I've ever come across it in a situation where it's made a material difference. One or two patients have mentioned it but ... (ED05)

Whether a patient is asked if he or she has an advance directive on admission to hospital may be directly linked to the level of use of advance directives in the general population. Until more people have advance directives, it is unlikely that hospitals will insist on a policy change.

Legality

In 1993, the British Medical Association (BMA) stated that:

...the possibility of patients inadvertently misdirecting their doctors by an inadequate appreciation of the circumstances or of the evolution of new treatments led the Association to recommend strongly that advance directives should not be legally binding on doctors, but legal cases in 1992 and 1993 indicated that an anticipatory decision which is clearly established and applicable to the circumstances would be as legally binding as any current decision made by a competent patient (*Cases referred to are Re T [1992] 4 All ER 649; and Airedale NHS Trust v Bland [1993] 1 All ER 859*) (BMA, 1993: 162).

The BMA had to change its recommendation to the medical profession in the light of several judgements in the English courts that gave common law authority to advance directives (*Re C* (1994)),

advance directives are always less conclusive evidence than the contemporaneous statement of a competent, informed, and autonomous person. The advance directive substitutes for the latter situation only to the extent that the patient, when competent, was well-informed, acting

reasonably freely, intending the instruction as now interpreted, and envisioning a situation reasonably similar to the one now faced. These concerns can be met fairly commonly, since ordinary persons giving advance directives are either giving thoughtful but broad instructions or are envisioning a future event that is known to be likely in that person's situation (*ibid.*).

Doctors interviewed in England were aware of and generally followed the BMA guidance. Choice in medical treatments means extending best clinical practice to ensure that all people have choices of where and how they are treated. The inclusion of patient preferences in medical records will help patients to set out their wishes and give them the opportunity to refer to an advance directive if they have one. The Government has published the draft Mental Capacity Bill (Bill 120), which is designed to give greater choice to people who are mentally incapacitated. The draft Bill would allow people to appoint attorneys to represent their views in healthcare decisions if they lost capacity in the future and to make advance decisions about treatment preferences if they wish to do so (Clause 9)³⁴.

English doctors were also aware of the problems that might arise from an advance directive. As in Scotland and the Netherlands, a major one is the time factor,

It is likely that living wills will be made many years prior to becoming incompetent, when details of the conditions specified - including possible treatments available - cannot be foreseen. There are many scenarios where a legally binding living will could bring about a distressing situation, which the person was trying to avoid. In such cases, legally binding living wills will prohibit doctors from providing the most appropriate palliative care available (ED08).

Consequently, if the content of an advance directive is not updated regularly especially in relation to progress in medical treatments, problems may arise when that directive comes into operation. Whether this would have any impact on the validity (perceived or actual) of the advance directive in everyday patient treatment and care within the NHS is speculative. This may be a factor influencing the ways in which healthcare professionals view the legal nature of advance directives and subsequently how binding they believe directives to be. When asked about the

³⁴ The Bill had its third reading in the House of Commons on 14 December 2004 and will have its second reading in the House of Lords on 10 January 2005.

legality of advance directives, doctors raised a number of points and some of the elements that may jeopardise that legitimacy are examined below.

Elderly

In care of the elderly, a group of doctors had previously discussed the validity of advance directives. Those clinicians agreed that, provided certain fundamental conditions apply, the document would be treated as valid. Other issues raised were:

First, there is the question of whether they should be revised and we actually discussed that as well and what is a reasonable period for revision and so on? Secondly, is the condition contemplated in the Will genuine at the moment? That's a clinical ethical judgement really, to see [that] those conditions apply. And thirdly, whether any overriding, more recent, statement has been made; they may have changed their minds (ED03).

Neurology

In contrast, neurologists interviewed felt that they could not make a decision on whether an advance statement was valid without further professional advice. While keeping a relatively open mind, one believed that it was,

...a situation to [be] put it in the hands of the lawyers really. If it appeared to be legally valid and expressed the patient's wishes, and obviously the patient's wishes are always paramount, [then we would act on it. But] I think I'd want a second opinion from the lawyer (ED06).

For oral advance directives, the situation is even less clear and doctors found them difficult to follow.

... well, again, obviously it's much more difficult to validate it and ... we just have to do everything we reasonably can to try and establish that that was [his or] her wishes. I think the situation that we come across more is with people with dementia, where they've expressed wishes but they don't appear to be totally rational based on the situation. It's usually not so much a matter of life or death or not as stark as that but it's usually somebody who is totally disabled and requires 24-hour care and wants to go home. I think we play those sorts of situations by ear (ED05).

Oncology

Finally, the oncologists interviewed had little experience of advance directives. They did acknowledge that case law probably existed on the subject, but nonetheless, were

unconvinced of a directive's legally binding value. Below is a typical example of the stance taken,

I think probably they're not legally binding. There may have been some cases to explore the legal standing of things like living wills. If there is, I'm just not familiar with it, I've never come across it. It's never affected me as a consultant, a so-called advance directive. Only once did I see a patient in here that had a sticky label on the front of their notes saying "living will" and it was incorporated into their notes but the patient was fine so it didn't arise. Nevertheless I'm in favour; I think they're a very good idea. I think, under the circumstances that we've been talking about, where somebody perhaps is terribly ill or disabled or can't talk or has had a devastating illness, something like this can be hugely helpful for the doctors and for the patient's relatives (ED07).

Although the oncologists interviewed did not believe that advance directives were binding on treatment decision-making, they were nevertheless still in favour of them being an indication of a patient's wishes. They also saw them as being an aid to healthcare staff and families, and from this it might be supposed that the English doctors interviewed would take advance directives seriously. This uncertainty about the legality of advance directives and their impact on actual practice is a common theme to each jurisdiction and will be dealt with in more detail in Chapter Seven.

Overriding an advance directive

It appears that doctors interviewed in England were happy to consider advance directives in decision-making for *incapax* patients and in some cases would even accept that they might be legally bound by them. This then raises the question of the circumstances in which they would feel entitled to override an advance directive.

Elderly

In elderly care doctor interviewed, in agreement with their earlier consensus, said that overriding a directive would not be carried out without due consideration of the circumstances.

I don't think you have a right to override it at any stage if it is clear that the advance directive contemplated the situation that you are currently dealing with and if there are no grounds to believe that the advance directive is no longer [valid]. So if it matches those prerequisites then I think you have an ethical duty as well as a legal duty [to comply with it] (ED01).

By admitting to an ethical and legal duty to comply with an advance directive, this doctor implies that advance directives have legal authority and therefore should not be overridden unless certain circumstances apply.

Neurology

One neurologist was aware of the potential validity of a directive, and like his colleagues in elderly care, did not think that a decision to override it would be taken lightly. However, in an emergency, where the patient had a good chance of survival, ignoring the prior refusal of treatment might be the most obvious course of action,

I think you'd have to have a very good reason for going against it. You'd obviously need to be convinced that it's valid; if you are then I think you'd have to have extremely good reason. I can conceive of situations where it just might be a clinical happenstance, which hadn't been catered for in the wording of the document, but in an emergency situation, if somebody had signed an advance directive saying "No CPR [resuscitation]", if I was an anaesthetist and I was anaesthetising for an operation and they had a ventricular fibrillation during the operation, then I would certainly defibrillate or do something to try to restart the heart regardless of any advance directive because I think that's a potentially very reversible situation (ED05).

This doctor stated that he would comply with an advance directive unless the situation was one in which a doctor could save the person's life. This is an inherent problem with advance directives due to the difficulty of specifying the treatments, which the person wishes to refuse in specified circumstances.

Oncology

The oncologists interviewed also agreed that the circumstances of the incapacity dictated whether they would override the directive as the physician in charge of the treatment.

It's quite a hard one because I think if someone is temporarily incapacitated, by nature of the disease and they may get better or if it can be reversed, then I think you've got to look at it very closely. If whatever's happened to them is never likely to get better and they're going to stay in that state forever and a day, or they're going to get worse, then I think you should look at it and say, right, that's it. With the treatments we've got, we can't do any more and they

either come out of it or they don't. Give a timescale and if nothing's changed then say, right, we'll go along with their wishes (ED07).

The decision on whether to override an advance directive seems to go hand in hand with how doctors view their legal status. If the doctors interviewed felt that they should consider an advance directive as binding then overriding it would be a serious matter. Additionally, a decision to override the directive may depend on the medical circumstances, and the potential recovery or success of the treatment and not by the personal attitude towards advance directives by the individual doctors. In this situation the view of the doctor on the binding nature of the directive may not even enter into the debate.

Patient Autonomy

All doctors interviewed assessed the use of advance directives as a valuable method of supporting and even increasing patient autonomy.

Elderly

One geriatrician discussed in detail the experience of a dying patient who had drawn up a living will. The will was followed by the doctor, but not blindly; he was able to comply with patient's instructions, explain to the family what was happening, and allow the patient to die without pain and with dignity and without compromising his professional autonomy. He explained,

...one of the strengths of her particular living will was that it was very explicit. It said, "if these conditions prevail, then I don't want antibiotics, intravenous feeding or any fluid support", it actually said that. I discussed it with her adult children, particularly her son who was interested in medical things, although not a medic himself. They said "this is what it said, why are you giving intravenous fluids?" And I said, "well we have to come to terms with what she wants. I know we're not giving her antibiotics and we don't plan to give her antibiotics", but after about 24 hours we discussed what would be the consequences of withdrawing fluids. I said, "if we carry on giving her fluids, it could be weeks before she gets pneumonia and we're not going to treat that. But if we stop fluids, she'll become dehydrated, she'll go into acute renal failure, she'll become delirious and she'll require possibly some morphine, and she'll die within a few days" and that's exactly what happened. It was extremely helpful to have the living will saying that "under

these conditions, I do not want to have any fluids or antibiotics". So, to me, that was unbelievably useful (ED02).

Neurology

Neurologists interviewed agreed that advance directives can help strengthen patient autonomy, but that there was also an urgent need for patients to be counselled in what the directive actually involved. Counselling should preferably be undertaken with the patient's family doctor and it should never be merely an endorsement of another course of action.

There's no doubt that people's views change when they become ill, but nevertheless I think that signing an advance directive is a major issue and something that you need to think carefully about. There need to be safeguards to ensure that the person's wishes are really being taken into account. The [doctor] has to make sure the person understands what sort of situations the document is dealing with and that those are their wishes. If it's just a sort of ... doctor's signing passport photographs or something like that, then, it seems totally pointless and silly (ED04).

The suggestion that this neurologist makes is relevant. Many people may make advance directives without getting any legal or medical advice. Counselling a patient when they present an advance directive at the hospital may be the first time a doctor has had the opportunity to explain the implications of such a document to the patient.

Oncology

Since none of the oncologists interviewed had experience of actual advance directives or living wills, answers were essentially speculative. Nevertheless, they agreed that an advance directive could help direct the doctor in his or her decision-making, as well as being indicative of the patient's past wishes.

I think the specimen ones I've seen tend to say "if the following terrible things happen to me and I'm incapable or I'm needing artificial feeding or I'm needing prolonged ventilation", and they're pretty directive of what the patient wants the doctors to do, I think that's great. Any information like that is better than nothing (ED07).

While the doctors interviewed may believe that advance directives would be helpful to them in their decision-making for *incapax* patients, they did not necessarily wish to be legally bound by them. This may have implications on advance directives' use as protectors of patient autonomy.

Conscientious Objections

The final group of questions concerned conscientious objections to treating patients holding advance directives. The BMA (1995a) has issued guidelines instructing doctors, throughout the UK, who have such ethical objections, to pass their patients to colleagues who feel able to treat them and be responsive to the treatment directive. It was interesting to discover what the doctors interviewed thought of this instruction, and whether doctors should have such an escape from treating those patients.

Elderly

All consultants interviewed in care of the elderly believed that doctors should not have to treat patients with advance directives because of various ethical reasons. One doctor thought that the risk to the doctor's professional autonomy was a good enough reason to refuse to treat patients with living wills.

I think with all things, because [people] need to make choices; the same should apply to doctors. If they have a genuine objection to it, then it should be passed to someone who can maybe make decisions without it affecting their decision-making process. It's just the same as anyone else is allowed to make that decision, so their autonomy should be respected as well (ED01).

Another geriatrician approached the dilemma from a different perspective. What was important was that the medical team agreed on the treatment regime, and that the best interests of the patient would be served through such a consensus. To have a member of the healthcare team in disagreement would be disruptive to the patient's care.

I think that's terribly important, as that there should be not just consensus, but unanimity as to what is being done, because if you proceed without everybody actually agreeing to what you're doing, it is likely to cause enormous problems. You're more likely to actually trigger a process of legal enquiry or journalists getting involved and so on, which I think in that situation would not be in the interest of the patient (ED03).

Another consultant reiterated this explanation, but with the added point being made that this course of action should be clearly documented.

I think if the reasons for disagreeing with the team decision are something like conscientious objection or some other vested concern that does not allow them to go along with the team, a position should be taken along the lines of

the person being excused from involvement in that case. But that needs to be clearly spelt out and recorded so that there's no misunderstanding afterwards as to the process (ED02).

Neurology

Neurologists interviewed also agreed that doctors should be allowed to express a conscientious objection to advance directives.

I think if you are pressured to give or even not to give a treatment, and you disagree on conscience grounds, then yes, I think that the only solution is to hand it over to somebody who will [treat the patient]. I mean personally, it wouldn't arise because, if that's the patient's wishes, I would go along with it and I don't care whether it's a Jehovah's Witness and if he's in for a blood transfusion or what it is, if that's their wishes, that's fine (ED06).

Oncology

The situation was the same for oncologists interviewed, as long as the doctor who objected did not try to change the opinions of the rest of the team. In that situation, the doctor should automatically refer the patient to another consultant, and to do otherwise was viewed to be bad practice.

Oh, I think that would be the right thing to do, I think they should pass the patient on to somebody else. The problem I would have is if a doctor said "look, I am the man in charge of this patient, despite an advance directive and despite the fact that the family all agree with that, I want to take a different position". I feel the right way to handle that would be for that particular doctor to bail out of the care of the patient and invite a different specialist to start looking after them, who presumably would be more sensitive to the patient and their family's wishes (ED07).

Finally, in the light of their unanimous agreement that it would correct to pass the patient to another consultant, doctors were asked if this right to conscientious objections should extend further than the doctor, to other healthcare workers, or nursing staff.

Oh, yes, to some extent I think we have to accept that. I think you have to be sensitive to the wishes of nurses, paramedical staff and so on and if they feel very strongly that something should or should not be done, then they should have a chance to air their concerns. At the end of the day though it's the consultant that's in charge of the patient, I think the consultant, in general, would try and do his best for that patient, bearing in mind any advance directives that were an issue (ED10).

Conclusions

In normal circumstances, in England informed consent is required before medical treatment can be given, although consent or refusal may be implied. There is no statutory duty for medical practitioners to inform of patients of all treatment choices and the doctor may restrict treatment options available. As in the Netherlands and in Scotland, every competent patient has a right to refuse treatment, which cannot be overruled, but there is no duty to inform patients of that right. Although these principles are governed by common law with several High Court and Court of Appeal rulings, doctors interviewed often ask relatives for consent for treatment where the patient is incompetent.

No clear model of decision-making emerged from the interviews but a mainly paternalistic attitude prevailed among medical interviewees. Doctors in England hold positions of power with patients and families respecting them, however, problems arise where there is disagreement with doctor's decisions and poor communication with the health team. Additionally, some of the doctors interviewed ignore guidelines on policy and restrict the information given to patients.

Advance directives are viewed as refusals, and not demands, for treatment. Opinion amongst interviewees is mixed on the current legal status of advance directives in England although many of the interviewees are aware of the BMA guidelines on directives. Likewise, there is mixed opinion on the binding nature of advance directives and some doctors stated they would overrule directives even if they were legally binding.

Very few English doctors who were interviewed had experience of patients with advance directives, with most found with patients in care of the elderly and neurology.

Some interviewees thought that ethical or religious grounds are not thought to be good enough reasons to overrule advance directives and overriding them required serious consideration. Others, however, thought directives to be influential but that they would overrule them if they felt it necessary.

Finally, many interviewees thought that advance directives could strengthen the patient's autonomy in cases of incapacity, unless the patient was fully informed of all available choices, then advance directives may fail to protect patient's autonomy to its full extent. While directives might help doctor's decision-making, in certain circumstances they could also diminish medical autonomy.

Chapter Seven Comparison of Findings

Introduction

This chapter brings together the findings of Chapters Four, Five and Six and focuses on the answers to the research questions. Each question is answered by drawing on the literature reviewed in Chapter Two and the themes emerging from the data analysis in Chapters Four, Five and Six. The chapter is arranged in sections, each headed by a research question. The responses to the questions for each of the countries studied are compared and the findings are summarised in a table at the end of each section. Finally, the answers to the research questions are discussed and the general conclusions are drawn at the end of this chapter.

The research undertaken for this thesis is largely exploratory and because of the small number of interviews that were carried out, the findings cannot be generalised in any statistical sense. The findings and conclusions relate the experiences of the sixty interviewees in the three countries and they provide the evidential support to the conclusions that are reached

This chapter shows that statute or common law make little difference to how medical decision-making is made or to the authority of advance directives. Advance directives may increase patient autonomy through providing information about the patient's prior wishes; medical practitioners did not show too many concerns about erosion of their professional autonomy by advance directives as professional autonomy is still very strong throughout the jurisdictions investigated. The overall predominant factor arising was that the process of making an advance directive is the most helpful factor within the doctor-patient relationship as it promotes communication and dialogue.

The common ground in each of the countries studied was that while the patient retains capacity, consent is always required to carry out medical treatment and all such patients have the right to refuse treatment regardless of the consequences.

Advance directives are uncommon in all jurisdictions studied and most are found with elderly patients. Regardless of whether advance directives are legally binding in statute or common law, most of the doctors interviewed do not believe directives will legally bind them. In all cases, and subject to certain circumstances, conscientious objection to advance directives is both allowed and, agreed upon.

Ultimately, attitudes of the doctors interviewed were paramount in having advance directives followed with communication between doctor and patient being the essential element. Poor communication between doctor and patients causes conflicts in all three jurisdictions with a need for greater communication between doctor and patient and more openness in giving information to patients

The main differences found between the three countries centred on the following topics. In the Netherlands, decision-making for incapacitated patients predominantly uses the substituted judgement model, with the best interests model being used most in Scotland and England.

It is a statutory duty in the Netherlands to inform patients of the treatment choices available with the right to refuse treatment often being explained to the patient. In the UK, doctors do not have a duty to be told of all treatment choices available to them or of their right to refuse treatment. Regardless of whether there is a duty to inform patients, medical practitioners may withhold treatment choices from patients for a variety of reasons.

Doctors interviewed in Scotland and England appear to have a misinterpretation of the law on consent for patients without capacity and they often erroneously ask relatives to consent on the patient's behalf.

Advance directives in the Netherlands are governed by statute, with Dutch lawyers considering directives to be binding on doctors' decisions. Patients are often asked whether they have advance directives on their admission to hospital or nursing home and they can be influential on treatment decisions. In the UK, advance directives are regulated by common law and codes of practice guidelines. UK lawyers do consider them to be binding on medical decisions with patients unlikely to be asked about

having a directive on admission to hospital. In Scotland doctors will consider the advance directive in making a decision for an incapacitated patient, while in Eng a directive will be taken into account and some cases, probably followed.

Research Question One

How is medical decision-making carried out, and how does this relate to statute or common law provisions in the three jurisdictions?

This section shows that the Netherlands is moving towards using substituted judgement, as the main decision-making model for incapacitated patients, while Scotland and England still use the best interests model for the most part, but this may show signs of changing. In the Netherlands, the WGB0 statute is not really an important factor in decision-making; doctors can help define the rules, while still being aware of the law. Scottish legislation is making inroads by underpinning statutes with principles that must be followed, for example, taking a person's past and present wishes into consideration, and involving patient in treatment planning. English case law sets the ground rules on medical decision-making at present with codes of practice providing professional guidelines for medical practitioners throughout the UK. Nevertheless, Scottish and English doctors are still misinformed of and misinterpret the law regarding consent with doctors asking relatives for consent to treatment.

Decision-making – Capax Patients

As explained in Chapter One, every person, who is competent to do so, should have the opportunity to decide what happens to his or her body.

The interviewees in all countries said that they were happy for consent to be verbal and accepted that it may even be implied, with hospitals not requiring written consent for most treatments. Doctors in the Netherlands stated that presenting oneself for treatment is often taken to imply consent regardless of what the WGB0 (Art 450(1)) states.

It is legitimate for a doctor in the UK to accept implied consent from competent patients; it is the reality of the consent that is important, not the form and there is no legal distinction between written, oral or implied consent (Montgomery, 1997: 236). Neurologists interviewed in Scotland and England rely on implied consent stating that if patients do not refuse treatment by fighting it off, it goes ahead. One interviewee thought that the NHS could not work otherwise, especially if doctors had to go into all the details of treatment involved with every patient every time a procedure was to be carried out. However, there is no corresponding duty on doctors in any of the countries to inform competent patients of this right to refuse treatment.

There is a statutory duty on doctors in the Netherlands to inform patients of available treatment choices (WGBO, Art 448(1)) and Dutch lawyers believed that the majority of the public were aware of those rights. Although the doctor has a duty to inform patients of the treatment options, they may withhold information if they believe it will cause serious harm to the patient (Art 448(3)). There is no duty on doctors in the UK to inform patients of all treatment choices, it is up to the doctor in terms of his or her professional duty of care to decide which treatment options the patient may choose from.

Interviews with doctors in England showed that the doctor in charge could deliberately restrict treatment choices. Lawyers in the Netherlands felt that patients were not being given a full explanation of the alternatives available. There are several points that arise from doctors having sole responsibility for deciding which options to offer a patient: first, the doctor controls the doctor-patient relationship by selecting the treatment option and secondly controls the patient's view of his or her illness as, in the majority of cases, the doctor is the main or only source of information and knowledge. Third, the doctor also has a role in the rationing of resources through not offering futile treatments in the options presented to the patient.

In all three countries doctors stated that they respected patients' autonomy to make their own treatment decisions as long as patients had the capacity to do so. All the doctors interviewed stated that they encouraged patients to make their own decisions

and considered their wishes important. Elderly patients in the Netherlands looked to their doctors for help with treatment decision-making and often asked General Practitioners to help them decide on specialist treatment. Good and long-standing relationships between doctor and patient enable decision-making to become a collaborative effort, especially where GPs have known patients for long periods of time. Geriatricians reported that elderly patients in England were happy to abdicate their autonomy to the doctor, in the belief that “doctor knows best” and that they were prepared to take the decision for the patient, acting in the patient’s best interests. In Scotland, doctors said that patients’ wishes were respected as much as possible and in oncology special relationships between doctors and patients often developed because of the nature of the patient’s illness.

Decision-making – *Incapax* Patients

Decision-making for patients who no longer have capacity varies to some extent between the three countries but, in all three countries, consent is still required. In the Netherlands, the WBO (Art 465(3)), and in Scotland, the AWI Act (section 16), authorise proxies to consent on behalf of the patient. Prior to the AWI Act, in Scotland the courts could appoint a tutor dative with powers to act on behalf of the incapacitated adult. The welfare attorney (section 16, AWI Act) fulfils a similar function and if no one is appointed, the doctor has a “general authority to treat” (section 47, AWI Act). In England, consent can only be obtained from the person who is to receive care. While persons who are aware that they are likely to become incompetent can hope to make their views known at a later stage, by appointing someone to speak for them, English law currently does not recognise rights of proxy consent on behalf of an adult. Where an adult is incapable of giving consent and requires treatment, the House of Lords has held that healthcare professionals are obliged to treat their patients in accordance with their best interests (*F v. W. Berkshire HA* [1989] 2 All ER 545). Providing they do so, there is no need for prior authorisation from the court.

In the Netherlands, the patient may have appointed a proxy and it would then fall to the proxy to refuse or consent to treatment on the patient’s behalf. If the proxy has prior knowledge of the person’s wishes, he or she cannot go against those wishes and

proxies have the right to challenge doctors' on the patient's behalf. If all else fails, the court can appoint a representative to give consent on behalf of the patient.

Doctors in Scotland and England claimed that implied consent respects patients' autonomy. Consent could be assumed unless a refusal by the patient was communicated through signs or gestures. Some Scottish doctors employ a type of hierarchy of capacity to decide whether a patient can give consent, for example, in less serious decisions (dressing a wound or removal of sutures, etc.) the patient's co-operation may be sufficient, while more significant decisions (consent to an operation) will require more explicit consent.

Evidence of the patient's previous wishes, including an advance directive, are collected from the family by some Scottish neurologists and some elderly care doctors in England attempt to determine what the patient's previous wishes were by consulting with relatives and friends.

In the Netherlands, Scotland and England and Wales, relatives often wrongly believe that they have the right to make decisions in the event of their next of kin's incapacity. In Scotland, doctors sometimes ask relatives to consent to treatment and by so doing, doctors wrongly give relatives the impression that they have the authority to give or refuse consent for treatment. In England, doctors also wrongly ask relatives to consent to medical treatment on their next of kin's behalf. Geriatricians and neurologists in Scotland and in England also assume that the patient consents to treatment unless he or she has obviously refused. However, it was pointed out that this practice is decreasing as more doctors become more legally aware.

Relatives and friends do not have authority to consent or refuse treatment unless they are appointed as welfare attorneys under the AWI Act in Scotland and this option is not available in England in England (Ashton: 1995: 187). The BMA has given advice on the matter,

Wherever possible, the doctor should involve those close to the patient in the decision-making process. If the patient has previously been autonomous,

decisions should be based on the patients' known views and preferences. People close to the patient can reflect those (Sommerville, 1993: 16).

Some Scottish doctors would seek additional legal advice if there was difficulty and, although this is preferable to acting outside the law, the BMA does warn that 'doctors cannot rely entirely on the law for clarification of their duties, since the application of legal maxims to specific cases is often subject to complex and variable interpretation' (Sommerville, 1993: 157). This seems to leave doctors in a difficult situation and it is understandable why there has been a call for clarification of the law dealing with incapacity in both Scotland and England.

It is clearly not routine for doctors in Scotland or in England to approach the patient, before any future incapacity, for advance decision-making and consent to treatment. While the doctor-patient relationship was mentioned as being important, the only doctors to discuss future treatments with their patients were oncologists. In England, some treatment decisions were made prior to incapacity. In England, there are currently no definitive legal rules explaining how medical decisions can be made for *incapax* patients and, unless the case goes to court, doctors can override the patient's wishes, where they are known. Good relationships between doctors and patients are important in helping patients come to appropriate treatment decisions, especially since patients often look to the doctor for advice and help with decision-making.

In Chapter Two, two models on which doctors could base their decision-making for *incapax* patients were outlined - the "best interests" model and the "substituted-judgement" model. In substituted judgement, the doctor tries to place him or herself in the patient's position and makes decisions on the patient's behalf. The court, in *Saikewicz* at 431 stated that

principles of equality and respect for all individuals require a substituted judgement decision-making standard that guarantees incompetent individuals have the same rights as competent individuals to refuse and terminate medical treatment (*Saikewicz*, 1977 at 431)

In the Netherlands, as is required by the WGBO, the "substituted judgement" model was used most often, especially in nursing home medicine. However, doctors in the Netherlands who chose substituted judgement as their preferred method of decision-

making with incapacitated patients looked to the first three subjective criteria (the expressed preferences of the patient; the patient's religious beliefs, if any; and the impact of the patient's family). Some doctors believed that if the patient's autonomy was to be respected, then an attempt ought to be made to recreate the situation that he or she would have wanted. Although the family could help in that reconstruction, respecting patient autonomy did not necessarily mean following the family's requests.

Substituted judgement is only useful where the decision-maker knows what the patient would have wanted (Deverette, 1995: 111). Therefore, in situations where it was impossible to determine the patients' wishes, some doctors used substituted judgement and others used the best interests model to make decisions. The best interests model was used most often. A similar example of a decision-making hierarchy is developed by Deverette (*ibid*, 113-115). At level one the substituted judgement standard is used and the patients' wishes are carried out; at level two best interests are used to decide what is in the best interests of the patient. Level three decisions would be made on the basis of what is reasonable treatment in the circumstances if the patient has left no indication of his or her wishes and has no interests because of the permanent loss of all awareness.

Some Dutch doctors believe that employing best interests is a surer method of decision-making since substituted judgement could be little better than chance. This view confirmed Dubler's findings that only half of the decisions made by proxies, using substituted judgement, agreed with decisions the patients would have made themselves (Dubler, 1995: 298-301).

Patient autonomy appeared to be less important in Scotland with the best interests model used most often. In neurology this happens even if it goes against a patient's previous wishes. The best interests standard has been defined as 'acting so as to promote maximally the good of the individual' (Buchanan and Brock, 1989: 88). If taken literally and without qualification, doctors would have to evaluate all the options and act in a way that provides the best outcome for the individual in question (Kopelman, 1997: 278). Clearly doctors find this difficult as no consideration is taken of the patient's wishes or religious beliefs, or of instructions left by way of an

advance directive, or of other patients’ needs. It is no wonder that doctors admitted they found use of both substituted judgement and best interests to be problematic. When incapacitated persons have periods of lucidity when they were able to make their own decisions, further problems in making treatment decisions were encountered.

Scottish doctors mentioned their difficulty in understanding the law relating to incapacity. Scottish lawyers, on the other hand, were less sympathetic and believed the law surrounding medical decision-making was less difficult to understand than often was made out. Lawyers in England thought doctors should take the responsibility for decision-making and that advance directives could help doctors make decisions.

In England, among the medical interviewees, no clear model of decision-making was apparent; the only definitive statement being that substituted judgement was not used in elderly care because of the reported lack of reliable persons authorised to act for the patient. When doctors found it difficult to establish patients’ wishes and were worried that they might make the wrong decision they used the best interests model. They thought it was a safer option especially if there were few relatives or friends to ask what the patient would have wanted. Having a person to act as an advocate for the patient and to argue his or her case was helpful for healthcare staff as long as these other perspectives did not interfere with decision-making.

The Law and Decision-making

The role of statute law and common law in medical decision-making in each of the three countries is set out in table 7.1 below.

7.1 Laws on decision-making

<i>COUNTRY</i>	<i>STATUTE LAW</i>	<i>COMMON LAW</i>
Netherlands	Yes (WGBO)	Infrequent
Scotland	Yes (AWI Act)	Yes
England	No	Yes

In the Netherlands, statute law in the form of the Law on Contracts for Medical Treatment (WGBO) lays down the rules concerning the aspects of medical treatment decision-making for both *capax* and *incapax* patients. Markenstein (1995) called it a "Special Contract" because it is associated with extraordinary rules within the civil code. The legislator used this type of contract in an attempt to redress the imbalance of power between the doctor and the patient by placing more obligations and duties on the doctor and giving rights to the patient. As a result, doctors' obligations are wide and patients' are narrow. There is a facility to override representatives' wishes if they do not satisfy the 'the standard of care required of a competent care provider' (Article 453).

In Scotland, the Adults with Incapacity (Scotland) Act 2000, controls the area of decision-making for patients who no longer have the capacity to consent or refuse treatment for physical conditions. The general principles of the Act state that the past and present wishes of the patient should be taken into consideration when treatment decisions are made. The Mental Health (Scotland) Act 1984, to be superseded by the Mental Health (Care and Treatment) (Scotland) Act 2003, covers treatment decisions for mental health disorders. It provides a statutory basis for advance statements concerning advance planning of treatments in mental health only. Patients without capacity can have treatment decisions made for them through a representative or a proxy.

The common law is the current authority for medical decision-making. In England and Wales, there is currently no statutory incapacity law that allows decisions for *incapax* patients to be made for physical treatments. The Mental Health Act 1983 covers mental health disorders and the Mental Capacity Bill covering aspects of decision-making, medical or otherwise, for incapable adults has recently had its third reading in the House of Commons. This Bill will not only bring the law governing welfare, financial and medical provisions for *incapax* patients in England and Wales into line with Scottish legislation but it will actually provide statutory authorisation for advance statements. Codes of Practice concerning medical ethics, withholding and withdrawing treatment, and advance statements written by the BMA and the GMC are extensive.

Litigation against doctors in issues of medical decision-making is rare in all of the three jurisdictions. According to many of the lawyers interviewed, most courts in the Netherlands have a great respect for clinicians' opinions. Lawyers in Scotland thought litigation was rare, costly and cumbersome and pointed out that help was available only for those who qualified for Legal Aid. In England, lawyers suggested that litigation was also infrequent and that the cost of medical treatment actions was prohibitive for a large section of the public who did not qualify for Legal Aid. Lawyers instead advised and encouraged families to talk to each other and their healthcare professionals before embarking on litigation.

Written advance statements are recognised in statute in the Netherlands (WGBO, Art 450(3)). A major case in 1989 was influential in encouraging campaigners to push for legislative backing and lawyers said they were happy that medical treatment and advance statements are now covered in law. Doctors on the other hand, did not believe that codification of the procedures regulating advance statements had produced any real changes in how medical decisions were made. They were concerned that they would be compelled to follow requests for treatment that may be futile or even illegal.

Consent procedures for *incapax* patients and issues surrounding medical treatment are now covered by statute in Scotland (AWI Act). Formerly case law (mostly English) had been relied upon for guidance by medical and legal professionals. The Scottish Executive decided against making statutory provision for advance statements when the AWI Bill was considered by the Scottish Parliament. Religious objections were exemplified by the fear of 'euthanasia by the backdoor' (interview with Policy Officer, CARE, 1999) and because of the need for other, more urgent provisions (Anderson, 2000). The AWI Act (section 1(4) (a)) states, however, that account must be taken of a patient's present and past wishes, which may, by implication, give some sort of statutory authorisation to advance directives. Doctors seemed to be happy with the informal provisions on advance statements provided by the Code of Practice (BMA, 1995a), as did lawyers, who did not believe it was

necessary to make statutory provision for advance statements and that professional regulation was sufficient.

Patients' rights in England and Wales are primarily grounded in the common law. Until the Mental Capacity Bill becomes law, only case law provides any legislative authority (*Re T* 1992; *Airedale NHS Trust v. Bland* 1993; *Re C* 1994; *Re AK* 2001; *Re B* 2002). Doctors were concerned that giving advance statements statutory backing would infringe their professional autonomy to make medical treatment decisions. They stated that they would not be happy being confined by more prescriptive rules (BMA, 1995a). Lawyers reported a high degree of misunderstanding among doctors and the public in the area of treatment decision-making and consent and, while they were happy with the common law, felt that rules that are more definite would provide greater clarity.

The main findings in relation to question one are set out below.

7.2 Summary of comparisons for research question one

How is medical decision-making carried out, and how does this relate to statute or common law provisions in the three jurisdictions?

Question One	Netherlands	Scotland	England
Decision-making - capax patients	Informed consent required – may be implied Statutory duty to inform patients of available treatment choices – certain conditions may allow overruling by doctor. Right to refuse treatment cannot be overruled – no duty to inform patients	Informed consent required – may be implied No duty to inform patients of available treatment choices Doctor may restrict treatment options available Right to refuse treatment cannot be overruled – no duty to inform patients	Informed consent required – may be implied No duty to inform patients of available treatment choices Doctor may restrict treatment options available Right to refuse treatment cannot be overruled – no duty to inform patients
Decision-making - incapax patients (Doctors)	Statute (WGBO) Informed consent required – may be implied, by proxy or AD	Statute (AWI Act) and common law Informed consent required – may be implied Implied refusal Ask relatives for consent	Governed by common law Informed consent required – may be implied Implied refusal Ask relatives for consent
Decision-making models	Substituted judgement or a combination of substituted judgement and best interests	Best interests	No clear model but mainly paternalistic
Statute law	Strong (<i>capax</i> & <i>incapax</i> patients) – WGBO	Strong for <i>incapax</i> patients only – AWI Act	Nil (at present)
Common law	Rare	English case law highly influential	Strong – several High Court and Court of Appeal rulings
Advance directives	In statute – WGBO	Common law – English cases mainly (only one Scottish case) May be implied by statute - AWI Act	Common law

Research Question Two

What are the processes of treatment decision-making for incapax patients and how are they related to doctors' professional autonomy?

All three jurisdictions foster a "doctor knows best" attitude among the population with a prevailing attitude of paternalism among medical practitioners. Decisions for incompetent patients reflect medical autonomy with decisions most often being made in the patient's best interests.

The doctors' positions of power allow them to make the rules, often ignoring policies or guidelines especially in the UK. Poor communication, withholding information, secrecy and lack of knowledge can all result in conflict between families and healthcare members.

Medical Authority and its Challenges

Doctors occupy a powerful social position that is intrinsic to the practice of medicine - often the doctor decides and the patient fits in with this decision. Patients can expect to be at a disadvantage because of their lack of knowledge and lack of training. Sometimes they 'want to believe the doctor is all knowing and all powerful and therefore will definitely provide the correct diagnosis and provide a complete cure' (Jones, 1999: 129). That is perhaps why, in the Netherlands, although statute controls doctors' powers over treatment decision-making, patients, particularly elderly patients still are said to feel that "doctor knows best". In Scotland there seemed to a "blanket" trust in doctors' authority and ability. This trust may be built on the belief that doctors are technically proficient, competent and committed to protecting the patient's interests (Mechanic, 2004: 1418-9) and patients were usually willing to go along with the doctor's decision, even if their own autonomy was overruled. Care of the elderly doctors in Scotland said that they would happily override the patient's wishes if they felt that they were irrational.

In oncology, the doctor-patient relationship was reported to be less paternalistic than other specialties. Often because the relationship has had more time to develop, oncologists stated they were more likely to go along with treatment decisions of their

patients. English oncologists likewise claimed that they were moving away from the paternalistic position of “doctor knows best”, towards a more evenly balanced partnership. This provides support for Jones (1999) who claims paternalism is no longer the primary model of interaction between doctor and patient and that good relationships are ‘built upon truth and integrity and the trust that this creates’ (*ibid*: 104).

While many patients in all three jurisdictions are said to bow to the doctor’s authority, both relatives and colleagues may challenge medical decisions. Conflicts can arise with the patient’s family and in an effort to ease disputes Dutch doctors might compromise with families, unless futile treatment was requested. Lawyers in the Netherlands are seldom involved in disputes between doctor and patient, but stated that, in any disagreement about treatment decisions, the *incapax* patient’s proxy need to take responsibility and challenge the doctor’s decision on the patient’s behalf. In cases that do go to court, doctors’ opinions and judgements were taken seriously by the court and were rarely overruled.

In all areas, challenges to the doctors’ authority usually come from relatives of patients who have lost capacity. English legal respondents thought that statute law, e.g. the forthcoming mental capacity legislation, might curb litigation, but offered few conclusions on whether statute law would keep medical power in check. It would appear that even where statute law does exist, as in the Netherlands, decisions reflect professional autonomy.

The family sometimes may disagree with treatment decisions made by the doctor. However, according to some interviewees, this may have nothing to do with the actual treatment decision and may be caused by separate family issues such as guilt and unresolved issues in past relationships. Family members may disagree about what the patient’s best interests are and doctors in Scotland felt that conflicts with relatives are often due to their unrealistic expectations of what treatment could achieve.

The patient’s prior wishes can also fuel conflicts between families and doctors. Treatment decisions that respect and enhance the autonomy of the patient may at the

same time disregard the views of the patient's caregivers and the rest of his or her family (Hardwig, 1995: 24). From the English doctors' perspective, the clinician's duty of care takes precedence - some doctors will yield to the relatives if there is no harm to the patient, but, if there is suffering, the doctor makes the final decision.

Medical respondents in England believed that lack of knowledge and lack of consensus on what the patient wanted could cause conflicts within the family and between the family and doctors. Neurologists believed that poor communication and the need for relatives to become involved in the patient's care could cause unnecessary conflicts. Poor communication was mentioned by medical respondents in Scotland and England as being the cause of disagreements among professionals and between professionals and relatives. A study of more than 400 doctors and nurses who were involved in life-support decisions for about 100 patients found conflict occurred between family members and healthcare staff in about half of these cases. Just as frequently there was tension among staff members and in about one quarter of cases, family members had conflicts with each other. Communication was again an issue and it was found that,

although conflicts between families and doctors usually involve a disagreement on whether to withdraw or continue life support, in many cases problems arise due to poor communication or other issues (Mulvihill, 2001: 284).

As a solution, Dutch doctors reported that more information, better communication with, and sensitivity to the family's concerns are valuable in avoiding and resolving conflicts. Support groups draw attention to the stresses families are encountering at this time,

We must also recognize that families are not simply or even primarily *patient support systems*. They must not be thought of or treated that way by doctors, hospitals, health care planners, or bioethicists. To do so is immoral, as Kant made plain. It involves treating the rest of the patient's family as mere means to the preferences of the patient (Hardwig, 1995: 23).

Conflicts might arise when differences of opinion are seen by medical practitioners as "wrong" treatment decisions because they are decisions that the doctor would not make (Jones, 1999: 103).

In Scotland, doctors who cared for the elderly would consider calling for a psychological/psychiatric assessment if there were disagreements with the doctor's treatment plans. Age Concern has advised that doctors should not assume that an irrational decision (to the physician) is inevitably due to mental disorder or incompetence and these patients should not automatically be presumed to lack decision-making capacity (Derse, 1999: 55). Resolution, according to several lawyers interviewed in the Netherlands and England, was more likely to be found through better communication with doctors, patients and families, explaining the benefits and effects of the treatments instead of resorting to the courts.

English lawyers are sometimes consulted by relatives who disagreed with the doctors' decisions to withhold treatment, typically where the doctor decides to stop treatment altogether. Lack of knowledge and inability to obtain information leads people to seek legal advice, often only to relieve their doubts and fears. Teff recommends greater communication by the medical profession and sees demands for greater participation in decision-making, as symptomatic of anti-paternalism in a society that feels 'indignation at the secrecy which often accompanies professional practices' (*ibid* 445). One English lawyer who was interviewed commented that problems can arise from secrecy and the concealment of information by medical practitioners and that this can lead to feelings of disempowerment by laypersons.

Most Dutch lawyers believed that, while the public were aware of their right to refuse treatment regardless of the consequences, they would prefer doctors to inform them of this right explicitly and to explain the alternatives more fully. Lawyers in England believed that patients should be told of their right to refuse treatment, to enable them to retain their personal autonomy. While they believed that doctors were acting in the patients' best interests by sometimes withholding this information, they were also concerned that it restricted the choices available to patients.

Doctors in all three countries said they did not routinely inform patients of their right to refuse treatment. Dutch doctors did not explicitly tell their patients as there was an implicit understanding that most people knew what their rights were and that patients

knew of their right to refuse treatment when they presented themselves for treatment. Many medical practitioners withheld this information, as some patients did not like to refuse treatments for fear of being left untreated altogether. In nursing home medicine, talking about the refusal of treatment to the patient was seen as leading to conflict and thought to be too distressing for patients. As a result, only CPR was routinely discussed with patients on admission to hospital or within the first few days. Some doctors were unsure about whether patients knew of their right to refuse – they thought the elderly probably did not, while younger patients were more likely to be aware of it. GPs were more likely to tell their patients about their right to refuse treatment, especially from a specialist, but this was expressed as a treatment option rather than an outright refusal. Finally, one doctor expressed the view that presenting oneself for treatment can be taken to imply consent regardless of what the WGBO states.

According to Scottish doctors, it is unusual for patients to be told of their right to refuse treatment. In care of the elderly medicine, they are told only if they specifically asked. In other cases, doctors only consult patients about their wishes regarding resuscitation issues. Some patients are told of their right to refuse treatment in neurology but consent often is implied so the question did not arise. Only if the procedure might be uncomfortable or invasive does the doctor offer the patient an opportunity to refuse, and patients are only asked about CPR because it was NHS policy. Only in oncology are patients regularly told of their right to refuse treatment. Doctors said it is important for the patient to know that he or she could refuse and to know everything about the treatment. However, one oncologist thought it was only up to the doctor to tell the patient of the best treatment option(s) available.

Similarly, in England, for doctors interviewed, it is not customary to tell patients of their right to refuse treatment and care of the elderly doctors do not inform patients, as it would increase their fears. In neurology, doctors rely on patients fighting off treatment if they did not want it; the onus is on the patients to show their refusal. Unlike their Scottish counterparts, English oncologists do not inform their patients that they could refuse treatment. Although guidelines have been issued by the NHS

(BMA *et al*, 2001) about asking patients resuscitations wishes, many English doctors interviewed did not even ask about CPR.

The main findings in relation to Question Two are set out below.

7.3 Summary of comparisons for research question two

What are the processes of treatment decision-making for incapax patients and how are they related to doctors' professional autonomy?

Question Two	NETHERLANDS	SCOTLAND	ENGLAND
Medical authority	Hold a position of power Respected by patients and families May restrict information given to patients	Hold a position of power Respected by patients and families	Hold a position of power Respected by patients and families Sometimes ignore guidelines on policy Restrict information given to patients
Right to refuse treatment	Held by all competent patients Statute law authority Patient not told of right to refuse treatment	Held by all competent patients Common law authority Patient not told of right - only asked about CPR	Held by all competent patients Common law authority Patient not told of right to refuse treatment
Challenges and problems	Family relationships may contribute to problems with doctors Poor communication with health team Withholding information from patients	Unrealistic expectations by families. Poor communication with health team Withholding information from patients	Disagreement with doctor's decisions Poor communication with health team Withholding information from patients

Research Question Three

How do doctors and lawyers view the current legal status of advance directives in each of the jurisdictions?

This section shows that regardless of the actual legal situations in each of the countries, most of the interviewees do not believe advance directives legally bind them. Opinion varies from directives being at best helpful, at worst an inconvenience. There is a need for more information on the legal situation in each of the countries and a need to be more aware of how others view advance directives, for example *'patients hope they are binding'*.

Definitions of Advance Directives

The Dutch Euthanasia Society (NVVE) usually supplies advance directives, drafted by a lawyer, in the Netherlands. There are two types³⁵: a *negative directive* (specifying the circumstances in which consent to treatment is refused); and a *positive declaration* where, the patient asks for something, e.g. resuscitation. Since 2001 a patient can ask for euthanasia in an advance directive, but the doctor is not compelled to carry out the request. Lawyers in the Netherlands are familiar with these documents and advise clients to write down their wishes after discussion with their family and their doctors and to give their GPs a copy to put in their files. Doctors interviewed in the Netherlands were familiar with and in favour of advance directives and encouraged patients to use them to express their wishes. They defined advance directives as being similar to testamentary wills, although witnesses are not always necessary (witnesses are not required by the WGBO). Oral directives often have a lower legal status, while some doctors would give them similar weight to written directives, others did not consider them valid. The majority of Dutch doctors interviewed expect patients to be asked whether they have an advance directive on admission to hospital, but they disagreed on when the most appropriate time might be to ask this question.

³⁵ See Chapter One for discussion of positive and negative treatment and oral directives.

There is an increasing awareness of advance directives in Scotland, with lawyers having some experience of drafting them and a few lawyers offered this service as a package, together with testamentary wills and powers of attorney. Lawyers interviewed in Scotland had seen few advance directives. Most were supplied by the Scottish euthanasia society, EXIT and could be downloaded from their website. Doctors expected that advance directives to be found mainly in care of the elderly and neurology. The majority of doctors interviewed felt that greater use of advance directives would be helpful for doctors in future decision-making, as the directive is a plan of management of the patient's future care. Doctors stated that they did not need be in writing, but if not they would prefer them to be witnessed by a medical professional. A neurologist stated that ideally the document would specify the treatment the patient wanted to refuse and that the patient could not demand futile treatment. The oncologists felt it would only be considered as an advisory statement that could be disregarded by the clinician, and that the next of kin and medical staff should agree with what is written in the document. Oral directives appeared to be used most often and discussed by patients and doctors most frequently in oncology.

In England and Wales, advance directives are uncommon amongst the interviewees and often originate from VES. Doctors in care of the elderly defined them as a refusal, not a demand, for treatment and ignored requests for futile treatment. The patient's wishes must be freely expressed and the directive should detail treatments and procedures that the patient does not wish to have. Oncologists would prefer it to be a written document but accepted that it also could be a video or a tape recording and noted that it should be witnessed and could be updated as necessary. Oncologists felt that advance directives would be useful in helping relatives discover and therefore assert their next of kin's wishes. Very few are used at present, and they are mostly found with patients in care of the elderly and neurology, but they could see that there is a potential for them to be used more in the future.

Care of the elderly doctors and neurologists interviewed in Scotland, did not ask patients if they had an advance directive at any point in their hospital care and none of doctors interviewed in England asked patients about them. Oncologists in Scotland said they did not ask specifically about advance directives because the

treatment regime would be discussed with the patient. Among doctors in the UK, medical opinion was that the onus was on the patient or relative to inform the doctor of an advance directive. This is consistent with BMA advice that the onus lies with the patient to ensure that the advance directive is properly drafted and is available for those whom it is addressed. The BMA suggests that patients who have made an advance directive should carry a card indicating this as well as lodging a copy with their doctor (BMA, 1993: 162). The opposite view was taken by lawyers in Scotland who thought that there should be an onus on persons with knowledge of the existence of such a document (next of kin, lawyers, GP, etc.), to inform the doctor dealing with the patient of the existence of an advance directive.

Legal Status of Advance Directives

Much decision-making concerning treatment for persons who have lost the capacity to give or refuse consent takes place without any clear understanding of their wishes, and a statement made by the patient setting out what he or she would consent to may be a way of preserving the patient's autonomy. Advance directives, as a way of documenting those wishes, may be a useful tool for the doctor in decision-making for *incapax* patients. To determine whether this is the case, doctors' and lawyers' views on the legal status of advance directives were elicited.

Lawyers interviewed in the Netherlands were happy with the way the WGBO protects patients' rights. The WGBO (Article 450(3)) only concerns advance directives (negative directives or refusals of treatment), requests for euthanasia (positive declarations) are contained in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001. These lawyers agreed that the law made advance directives legally binding on doctors' treatment decisions and that medical staff should comply with them unless there was a good reason for overriding them. The doctor could be held accountable for ignoring or overriding an advance directive and families could use this to challenge the doctor's treatment decisions. This puts a pressure on the doctor and the patient (and his or her family) has a device by which to challenge the medical professional, which may alter the potential power of parties involved.

In Scotland things are somewhat different. Lawyers did not believe that advance directives were legally binding on doctors and said they would advise clients that they were only persuasive in medical decision-making. One lawyer said that a discussion with a judge in Scotland verified that it was unlikely that an advance directive would be regarded as binding in Scotland if the consequences were that the person would die, a so-called "suicide-motivated directive". Despite these negative aspects, some of the lawyers who were interviewed thought that a legislative framework would introduce a welcome degree of certainty into the law in this area, and that it could provide a doctor with statutory immunity from civil or criminal liability if he or she withheld treatment either in accordance with a living will or on the instructions of a welfare attorney. Additionally, lawyers thought that doctors should be made aware of advance directives and the fact that they are duty bound to consider them in helping to make a treatment decision. However, lawyers believed that people making advance directives were not sufficiently aware of the complexities of the law in this area and noted that there were drafting difficulties, e.g. it is impossible to list all medical circumstances in which they would apply.

There is no statutory or case law relating to the legal status of advance directives' legal status in Scotland, although English case law would be highly influential in the Scottish courts. Presumably the courts will decide on their binding nature on a case-by-case basis. There was general agreement that oral statements carry less weight but should be respected nonetheless.

Opinion was mixed on the current legal status of advance directives among English lawyers. Most would advise that they should be taken into account when making treatment decisions, but that doctors would not be duty bound to follow them. Due to difficulties in interpretation and the uncertainty regarding their legality, lawyers stated that they would advise doctors that they need only consider them when making treatment decisions but that they would not be duty bound to follow them. They admitted, however, there may be some legal authority for directives at common law. BMA Code of Practice provided satisfactory guidance on advance directives for doctors, and they considered that the courts could fill any gaps.

Most Dutch doctors interviewed are aware of and well informed about advance directives, and were familiar with seeing patients who had them. Some doctors did not think they legally bound them, despite the fact they were clearly authorised by statute. In fact one GP went so far as to say that, if a patient disagreed with his treatment recommendations, he or she could get another doctor. Only three of the 10 Dutch doctors interviewed believed advance directives were legally binding and that they would be followed. Even the doctors who did believe that advance directives were legally binding thought that the doctors' views would prevail in the end; there is clearly a gap between the legal framework and the practical realities in this area of medical law. This may be caused by lack of knowledge of the law but for some doctors it was obvious that they felt their professional judgement was more important, regardless of what the law said.

In Scotland, doctors were not very well informed about the legal status of advance directives and most thought that they were only advisory. Only one doctor (in care of the elderly) thought he would be legally bound and this was probably because he had prior experience of a patient with a valid advance directive in England. Some doctors would be prepared to take oral as well as written directives into consideration but still did not believe them to be legally binding; others were unsure of their legality but would place a good deal of moral weight on them in any case. Doctors believed it would be unhelpful to place legal rules on advance directives and one oncologist felt it would be wrong to establish rules around decision-making as it could decrease the patient's quality of care by restricting the treatments available to them.

Like the Scottish doctors, English doctors interviewed were not very well informed about advance directives although some were aware of the BMA guidelines stating that advance statements should be followed in certain circumstances. They were aware of relevant case law on medical decision-making but were unconvinced that the courts would find that advance directives were legally binding on doctors. Nevertheless, many doctors were in favour of them and in care of the elderly medicine, doctors said they would treat advance directives as valid, provided certain fundamental conditions applied. Others wanted further legal opinion before making any decision based on what was written in an advance directive. When pressed,

neurologists did agree that if the advance directive was legally valid and expressed the patient's wishes, it would be acted upon. However, in the opinion of many doctors, legally binding advance directives could cause distressing medical situations for the patient and prevent doctors from providing the most appropriate form of treatment. In certain circumstances doctors said they would probably overrule an advance directive, even, if it was legally binding, to ensure that the best interests of the patient were satisfied. Oral statements created even greater difficulty - doctors were sure that they would have to be established as the patient's expressed wishes and that each statement would be examined and dealt with on its own merits.

In the light of other research carried out in the UK on knowledge of advance directives, it is perhaps unsurprising that doctors in the UK were misinformed of the legal nature of advance directives. Only half of GPs surveyed in London and Winchester were aware that some forms of advance directive could carry legal force (Bowker *et al*, 1998) and a postal survey investigating doctors' knowledge of advance directives in Dorset found 17 hospital doctors and 21 GPs had not heard of the BMA's guidance on advance statements (Zaman and Battock, 1998: 147). There is an obvious need for clear and unambiguous information to be given to the medical profession on advance directives.

The main findings in relation to research question 3 are set out below.

7.4 Summary of comparisons for research question three

How do doctors and lawyers view the current legal status of advance directives in each of the jurisdictions?

Question Three	<i>Netherlands</i>	<i>Scotland</i>	<i>England</i>
Definition of advance directives	Refusal of treatment (WGBO) Positive Declaration (euthanasia)	A plan of management of the patient's future care Refusal of treatment only	A refusal, not a demand, for treatment Refusal of treatment only
Legal status of advance directives - Lawyers' opinions	Legally binding	Not legally binding	Opinion mixed on the current legal status.
Legal status of advance directives – Doctors' opinions	Some doctors did not believe they would be legally bound, some did not know their legal status If in doubt the doctor's view would prevail	One doctor felt legally bound Majority only prepared to take both written and oral directives into consideration	Aware of the BMA guidelines on ADs. Mixed opinion on their binding nature Some doctors would overrule ADs even if they were binding

Research Question Four

Do doctors consider advance directives when making treatment decisions for incapax patients?

This data answering this question shows that decision-making for *incapax* patients can be helped by advance directives. In the Netherlands advance directives can be influential but the doctors interviewed stated that they could get round them by interpretation of the law and the circumstances. In Scotland doctors who were interviewed said they would consider them and follow them if they did not contradict the doctor's decision. In England advance directives are influential but doctors interviewed stated that they would overrule them if necessary.

Advance Directives and Decision-making

How doctors take account of advance directives when making treatment decisions depends on how much they believe they are bound by them and under what circumstances they feel they have a right to override them. Interview data from medical practitioners in all three countries indicates that doctors believe advance directives to be little more than advisory. Doctors are happy to follow a directive as long as certain conditions apply, but very few doctors feel they have to be legally bound by them. Some doctors would have no problem overriding a directive if they did not agree with it, but the majority would respect the patient's wishes and try to comply with what had been asked for.

Use of Advance Directives

Doctors in the Netherlands estimated that between 2% – 35% of their patients had advance directives. They stated that nursing home residents are the group most likely to make advance directives as they are usually made by elderly people and when they become more frail and ill.

In Scotland and England, doctors had very little experience of patients with advance directives so their responses were somewhat speculative and mainly anecdotal. Doctors interviewed estimated that between 2% - 4% of their patients in Scotland and between 2% - 7% in England held advance directives. Neurologists and

oncologists in Scotland and England had come across more oral directives than written and much of the advance care planning centred on CPR (possibly because NHS policy dictates that patients should be asked about this on admission). One doctor working in care of the elderly medicine in England commented that, in his view, certain types of people ('clear-thinking individuals') made advance directives, often many years before they are required. A study researching the type of person who used living wills, gave some support to this. The researchers found that patients who held living wills were likely to be female, white, and educated to degree level (Hanson and Rodgman, 1996). Another doctor, in neurology, postulated a link between the lack of strong family ties and the need to express future treatment wishes in a legal document. He felt it would be less common to feel the need to do so if close family ties existed.

Overriding Advance Directives and Conscientious Objections

Netherlands

Dutch law states that certain conditions must apply before a doctor can override a directive: if the doctor's duty of care and actions were within profession guidelines, this would constitute sufficient grounds to override the directive. On the other hand, doctors said that they did not believe an advance directive would completely legally bind them and it therefore can be assumed that there are circumstances in which doctors would override an advance directive. Indeed, some doctors stated that if their professional duty of care were threatened, they would ignore the instructions in the directive, often passing the patient to another doctor if there was a disagreement between doctor and patient.

Dutch lawyers interviewed stated that lawyers seldom become involved with healthcare issues and the courts rarely deal with cases relating to advance directives. Thus, there have been few challenges to a doctor's decision to override a directive. Even when a case does reach the Dutch courts, lawyers believed that a doctor's professional opinion would rarely be questioned. Many lawyers (50% of those interviewed) thought that advance directives should not be overridden by doctors or other healthcare providers, but lack of litigation in this area means that the courts

have had little chance to rule on this. The lawyers also pointed out that, since the medical disciplinary court of the KNMG would usually deal with conflicts in this area, lawyers have little experience of these disputes and were not in a position to comment further.

Dutch doctors were critical of advance directives that had been drafted without recourse to medical advice. They felt that lack of medical knowledge in drawing up a directive might either restrict the doctor in the palliative treatment he or she could offer or force the doctor to override the advance directive under article 453 which states:

The care provider must, in the course of his duties, have regard for the standard of care required of a competent care provider and must act in accordance with the responsibilities ensuing from the standard of professional care required of care providers.

An advance directive is restrictive if the doctor feels that the care he or she is allowed to provide is not in accordance with the professional standard of care expected in those circumstances. The doctor could then feel free to override the directive. One doctor went further when he stated that, as far as he was concerned, doctors could interpret the law and make it less robust by determining the standard of care that applied. In other words, since the medical practitioner decides, using professional protocols written by the medical profession themselves, on the standard of care in the Act, the profession is then at liberty to control much of what the patient can ask for in an advance directive. The state may make the law but the medical profession interprets it. Doctors can also decide what constitute 'cogent reasons' for ignoring an advance directive.

As mentioned above, the Act states that doctors cannot terminate the treatment contract unless there are good reasons for doing so (WGBO, Art 460). The Dutch doctors who were interviewed thought that conscientious objection would be a good enough reason to terminate the contract and some of them suggested that patients could find another doctor if the conflict could not be resolved. This is covered by the WGBO which states that the doctor may 'instruct others to perform [treatments] without prejudice to the liability of the care provider'. However, some doctors felt

that while clinicians were entitled to their own beliefs, allowing these beliefs to have some influences over treatment decisions could place the doctor's autonomy before that of the patient.

Scotland

The general principles stated in the AWI Act do not compel the doctor, in his or her decision-making, to follow the past wishes of the *incapax*. On the other hand case law does require the doctor to follow an advance directive, there have been no cases where a doctor has been taken to court for overriding or ignoring a patient's wishes either in an advance directive or through a representative.

The BMA code of practice allows doctors who have a conscientious objection to advance directives to pass the patient to another consultant (1995a). This was likened to Catholic doctors withdrawing from terminations of pregnancy cases and most of the Scottish doctors thought this were reasonable. A few misunderstood the advice from the BMA and thought that it required the doctor to treat the patient even if the doctor objected on moral grounds. These doctors did not approve and believed it would be wrong to continue to treat someone and ignore an advance directive because of the doctor's personal objections. One oncologist felt that if doctors worked in the NHS they should take all patients regardless of the circumstances and should not object to advance directives even if they specified a different decision to the one doctor would take. These views differ considerably from those in relation to circumstances in which doctors would override advance directives. It seems that doctors in Scotland disapprove of doctors going against patients' wishes because of their own religious or moral beliefs but thought it reasonable to override patients' wishes if they were irrational or unreasonable. It would appear that these doctors were setting their own autonomy (in the shape of religious and moral beliefs) aside in favour of the patients' best interests.

England

The lawyers interviewed in England believed that overriding advance directives was a serious decision and should only be taken after careful consideration by the doctor in charge. Sanctions should be applied to doctors who wrongly ignored a living will and, in some cases, it might be appropriate for society to register its disapproval

through the criminal law. Criminal sanctions were seen to be more important than civil remedies or a disciplinary action. English lawyers felt that, conscientious objection on ethical or religious grounds was not a good enough reason to overrule an advance directive and that referring the patient to a colleague was the appropriate course of action.

Some English doctors would override a patient's wishes if there were good reasons to do so, and these would usually be dictated by medical circumstances. Clinicians would consider the circumstances but unless the advance directive was no longer valid, there would be an ethical duty to follow it and they would only override it if there were very good reasons for doing so, for example, in an emergency and where the patient had a good chance of surviving. This attitude seems to ignore the reasons behind making an advance directive and implies that, if the treatment refused in the advance directive were to be effective, the doctor would override the directive and give the treatment and that the advance directive would only be followed if the treatment would not be successful. This pays lip service to the ideology behind extending patient capacity into incapacity and is illustrated by a GP writing in a medical journal who states,

It is absurd to say that there is no truth defined by experts, that patients are equals, or to allow patients to define conditions and treatment ... Clinical effectiveness depends on understanding the patient's beliefs and expectations. Patients are, however, not equals, and their beliefs do not have the ontological status of medical knowledge (McQueen: 2002: 1214).

The BMA and the GMC have issued guidelines on conscientious objection but doctors are not compelled to follow them³⁶. In the opinion of the majority of English doctors interviewed, that conscientious objection should be allowed as long as the doctor does not force his or her opinion on the rest of the team. It would be appropriate to refer the patient to another consultant and to extend this facility to other members of the healthcare team.

All the doctors interviewed in each jurisdiction, agreed that advance directives were useful in helping make treatment decisions for patients who have lost capacity. They

³⁶ These guidelines also apply to doctors in Scotland, but some Scottish doctors did not regard the guidelines as binding and other had not even heard of them.

also agreed that directives could not and should not be used to request futile treatment and, with the exception of the Netherlands, directives should be used only to specify refusals of treatment. They were used rarely at present, and again with the exception of the Netherlands, doctors did not ask patients if they held a directive on admission to hospital, or at any other time in their hospital stay. As advance directives are covered by statute in the Netherlands, this may be part of the reason behind the differences between the views of Dutch doctors and those of doctors in the UK. In Scotland and in England, while doctors do nothing to or deter patients from using advance directives and little effort is made by doctors to encourage their use.

A summary of the answers to question four is set out below.

7.5 Summary of comparisons for research question four

Do doctors consider advance directives when making treatment decisions for incapax patients?

Question Four	<i>Netherlands</i>	<i>Scotland</i>	<i>England</i>
<i>Use of advance directives</i>	Mostly found in Nursing Home Medicine. 2%-35%	Very rare but mostly found in care of the elderly and neurology 2%-4%	Very few, mostly found with patients in care of the elderly & neurology 2%-7%
<i>Asking about advance directives on admission to hospital</i>	Expect patients to be asked.	Did not ask Onus is on the patient or relative to inform the doctor of an AD.	Did not ask
<i>Conscientious Objection – lawyers’ opinions</i>	Difficult to comment	Only for good reason, e.g. religious or ethical reasons and AD should not be overridden	Ethical or religious grounds not a good enough reason to overrule an AD
<i>Conscientious Objection – doctors’ opinions</i>	Reasonable if the doctor can come to some agreement with the patient	The BMA and the GMC have issued guidelines but there is no strict duty to follow them	Allowed as long as the doctor did not force his or her opinion on the rest of the team
<i>Overriding an advance directive – lawyers’ opinions</i>	WGBO has a facility to override an AD	Up to the courts to decide whether to allow an overruling	Required serious consideration
<i>Overriding an advance directive – doctors’ opinions</i>	If duty of care is not compromised	If necessary and if AD was irrational	If good reasons to do so
<i>Impact of ADs on decision-making</i>	Influential but doctors can get round them if necessary	Consider & follow only if not against doctors’ decisions	Influential but would overrule them if felt necessary

Research Question Five

How do advance directives affect professional and patient autonomy and the balance of power between doctor and patient?

This section demonstrates how the interviewees thought advance directives related to medical autonomy. They felt that directives have the potential to restrict medical decision-making to some degree but doctors would override them if necessary. Individual autonomy may be strengthened by advance directives through reinforcing substituted judgement and self-determination but patients need to be informed about all treatment choices for them to be effective.

The balance of power between doctor and patient is undergoing minor changes. There is a move from paternalism towards giving greater weight to individual autonomy expressed by the patient, but this change is happening very slowly and the interviewees are unsure how much advance directives contribute to this change. It may be a natural development and move away from “doctor knows best” which is due to happen regardless of the presence of advance directives. The process of making advance directives – communication with healthcare providers, carers and family members, discussion of treatment options, and what the patient does not want in the way of medical treatment are all factors that also may have some impact on individual autonomy.

Professional Autonomy

Cruess and Cruess (1997) comment that maintenance of sufficient individual and professional autonomy³⁷ is necessary to enable the doctor to act in the best interests of the patient; and that the obligation to put the welfare of the patient and of society above their own is paramount.

In certain situations, respect for a patient’s autonomy may compromise the doctor’s duty of care: if a patient requires an operation to save his or her life, but refuses to consent to surgery, a doctor may believe that his or her duty of care may be at risk. If

³⁷ See Chapter Three for discussion of professional autonomy.

the patient is competent then it is unlikely that the doctor will be held responsible for any harm that comes to the patient, nevertheless the physician may still experience a shift in the balance of power over treatment decisions. Conversely, the law does not free the doctor from his or her duty of care because of a patient's adamant refusal if that refusal is either incompetent or unlawful and there is no valid advance directive to confirm the refusal. The dilemma for the doctor seems to be one of trying to respect patient autonomy while continuing to follow his or her duty to care for the patient's best interests. This may be where the problem lies: trying to resolve the tension between what the patient wants and what the doctor thinks the patient needs (Childress, 1982: 3). The solution may be found in looking at the doctor-patient relationship more as a partnership rather than as a benevolent healer-disadvantaged person.

Professional autonomy within the medical profession implies a contract between doctor and patient in order to improve the patient's health (Horner, 2000: 414). In the Netherlands this hypothetical contract has become a reality through the WGBO, which through the Law on Contracts for Medical Treatment states that:

The contract concerning medical treatment - hereinafter referred to in this part as the treatment contract - shall be the contract whereby a natural or legal person, the care provider, undertakes in respect of another, the principal, to carry out in the pursuance of a medical occupation or enterprise medical actions directly affecting the person of the principle or of a particular third party. The person thus directly affected is hereinafter referred to as the patient (Article 446(1)).

No formal contract between doctors and patients exists in the UK but a hypothetical contract in Horner's sense would be that of the doctor and the patient working together towards a common goal. It is not enough that this state of mind exists, however, as all parties must play their parts. The patient must give consent for the doctor to carry out any examination and any necessary procedures and, according to Horner, 'it also includes the right of the physician to refuse treatment which he or she judges to be futile or not in the patient's best interests' (*ibid*). It is at this point that both professional and patient autonomies may conflict.

The Dutch lawyers who were interviewed felt that patients often do not have adequate information on which to base their treatment choices. It is the function of the law to redress the imbalance between doctor and patient 'by providing patients with the 'right' to be given that information, or perhaps more accurately by imposing a duty on doctors to provide it' (Jones: 1999: 129). This was exactly what the legislators planned by inserting Medical Treatment Contracts into the Dutch civil code and explicitly placing a statutory duty on doctors to give patients the required information on which to make informed choices. When the physician chooses to withhold some information or choices, consent will be given only on the basis of the information given, which may be insufficient to enable the patient to make a fully informed decision.

Article 448(3) of the WGBO states that,

The care provider may withhold from the patient the information in question only if its provision would manifestly cause the latter serious harm.

This means that although doctors must explain the treatment choices available to the patient, they can restrict the amount or content of information given if it is in the patient's interests to do so. Withholding information may have some impact on how the patient views the treatment choices offered. However, by omitting to tell the patient he or she has a right to refuse treatment altogether, it may even avoid a refusal of consent. It can protect the doctor's professional autonomy by ensuring that the patient is only given choices of which the doctor approves. This is similar to the way Cantor (2001) describes Lukes' (1974) third dimension of power, where the patient's choices are shaped by the medical knowledge and the doctor's assessment of the available treatments. English lawyers indicated that doctor's autonomy and power rested on their control of information. According to one lawyer, patients frequently do not have sufficient information to protect their personal autonomy. Doctors are typically the main source of information and they have the power to give or withhold that information in the best interests of the patient.

According to one Dutch lawyer, advance directives can actually promote doctors' professional autonomy. Where this lawyer's medical clients had followed patients' wishes to withdraw or withhold treatment, they commented that they had felt

supported by advance directives, especially where the decision was not to treat the patient any further. In this situation the advance directive did three things: first, it fulfilled its role in protecting the patient's autonomy in making his or her wishes known. Second, the doctor's duty of care towards the patient was protected through a legal document. Third, it showed that the doctor respected the patient's autonomy by respecting the wishes as set down in the advance directive. Some of this lawyer's medical clients felt supported by advance directives as they allowed the doctor to withhold treatment knowing that he or she was acting with regard to the patient's wishes.

Advance directives could be made even more protective by being very explicit, and one Scottish interviewee thought their role in safeguarding patients' rights could be enhanced if they were disease-specific. Disease specific advance directives are designed specifically for people who have a particular disease and differ from generic advance directives in the instruction component of the directive (Singer, 1994: 594). There are several advantages to having an advance directive that deals with the specific illness of that patient: it can present a narrow range of choices making the treatment options easier to understand; the choices are more relevant than those in a generic advance directive; because the patient usually already has experience of the illness, the choices are less hypothetical, it is often difficult to make authentic choices in a generic directive as many of the choices offered are hypothetical. Finally, because the group of patients catered for in a disease-specific advance directive is limited to those with a particular illness, the prognostic information is more precise. The main disadvantage to disease-specific advance directives is that they often do not cater for events that are not associated with the primary disease but may sometimes occur. For example, an advance directive specifically dealing with the treatments of motor neurone disease may not consider implications of a sudden stroke (*ibid* 595).

GPs in the Netherlands reported that they often become mediators between patients and specialists, especially since patients have trouble saying "no thanks" if they do not want a particular treatment. The power doctors enjoy is a mystery to many patients and there are still people who think they have to do what the doctor says

because “doctor knows best”. Elderly patients, in particular, have great respect for the doctor’s authority and this may mean other agencies have to become involved in protecting patients’ rights.

Dutch doctors had mixed views on protection of their professional and personal autonomy. There are clearly problems for doctors in trying to reconcile respecting a patient’s autonomy with fulfilling their own duty of care. Some Dutch doctors were protective of their own autonomy, and as one put it, if a doctor’s duty of care was compromised by a patient’s treatment choice, then he or she might be asked to get another doctor.

In England, the doctors attributed their power to their social position of being a doctor rather than any actual legal powers they might have and that this was the most significant factor in protecting professional autonomy. According to some, it is often a case that the doctor decides and the patient fits in. Patients experience constraints on their power through having limited access in the NHS to doctors of their choice and finding it difficult to obtain second opinions. Patients who could not afford private healthcare would have difficulty if their NHS doctor did not agree to follow their advance directive. In this situation an advance directive would be valuable in supporting patient autonomy only if it did not compromise the doctor’s professional autonomy.

Some medical practitioners in England considered that if patients were going to benefit from advance directives and if there was to be an increase in their use, there would be a need for patient counselling. The patient, the GP and the family should all be made aware of what the directive actually involves. A few of the doctors were even more cautious and believed that directives could help the doctor in decision-making but only as an indication of the patient's wishes, since any information of that nature might prove to be helpful in the circumstances. There was a caveat, however, and autonomy would only be protected where the person was fully informed of the choices being made: discussion, explanation and openness between doctor and patient were all deemed essential.

From a different perspective, one lawyer expressed the opinion that treatment decisions that respect patient autonomy may, at the same time, disregard the doctor's professional autonomy causing a conflict of autonomies and possible disputes between the doctor and the patient or the doctor and relatives. That said, others agreed, and said that if patients were cognitively intact, doctors should respect their autonomy. Advance directives could help with this but they were not the only way of preserving patients' rights, since discussion of advance care plans should be ongoing throughout the treatment regime.

Individual Autonomy

Lawyers interviewed in all three jurisdictions considered that advance directives, as an additional protection of patients' rights, were becoming more popular among the public. Often, because of a patient's medical condition, an advance directive was the only way to determine the patient's wishes, and at times might be the only way to protect the patient's autonomy.

According to many interviewees, people in the Netherlands are well informed about healthcare because they are interested in their own wellbeing and personal autonomy. This was emphasised by Dutch lawyers who thought that a patient's autonomy was as important as a doctor's professional autonomy. One commented that an ill person is as wise or unwise as a well person is and should similarly be allowed to make irrational decisions. Just because a patient does not want the treatment recommended by the doctor it does not follow that he or she does not want to be treated. In conflicts with doctors, when a patient becomes incapacitated, advance directives can strengthen the patient's substituted judgement and support decisions made by a patient's representative.

Lawyers in the Netherlands said that the "doctor knows best" ethos still prevails, particularly among the elderly, but thought that the WGBO was helpful in reinforcing patient autonomy by giving legal authority to advance directives. In an attempt to normalise patients' attitude to doctors in the Netherlands – many still believe that doctors have power over life and death – legislators introduced the Medical Treatment Act, which attempted to balance the power of the doctor and the

patient. Advance directives were thought to be a way of helping doctors base their decisions on what patients want particularly where the patient's proxy is not available, and that, in some cases, they may be the sole indicator of the patient's wishes. According to some lawyers interviewed, the WGBO has not made a significant difference to the balance of power between the doctor and the patient. Dutch doctors interviewed did not feel that it had been necessary to pass such a law to protect patients' rights, however, lawyers were convinced that the WGBO and advance directives were helpful in protecting patients' rights and autonomy. They admitted that advance directives were not yet perfect but they were becoming more successful, giving the patient the right to initiate discussion with the healthcare team on decisions that could arise in the future. Because of this high value that society places on individual autonomy, advance directives that otherwise would have been ignored through lack of authority, were now being followed.

In Scotland, lawyers believed that traditionally there was a very paternalistic attitude by doctors towards *incapax* patients – they would be given treatment and no questions would be asked. A decline in the paternalism that existed before the AWI Act was considered a great advance in the protection of the patient's personal autonomy, and the Millan Consultations and subsequent 2003 Act³⁸ embodied a protection of autonomy perspective. The 2003 Act went further than the AWI Act did by granting legislative authority to advance directives concerning treatment for mental health disorders. A number of lawyers believed that a solution could be found through legislation. According to them, advance directives with some legal status were the way forward and the AWI Act and the forthcoming legislation on mental health issues show a desire to clarify the common law basis for treatment decision-making for vulnerable people. Despite legislative change and a move away from paternalism, doctors still could override advance directives if they considered them less than in the patient's best interests. The 2003 Act only requires that the doctor record his or her decision to go against the advance statement in the patient's medical records and to inform the Mental Welfare Commission.

³⁸ Mental Health (Care and Treatment) (Scotland) Act 2003

By enabling a patient to make an anticipatory decision regarding treatment, the advance directive can offer a person greater self-determination. Scottish lawyers felt that this was necessary because they believed that many doctors would not act on the explicit wishes of the patients and this was leading to an increase in litigation and complaints to the GMC. Conflict between the doctor's duty of beneficence and the patient's right to self-determination could cause discord between the doctor and the patient or between the doctor and the family if the patient was incapacitated. One solution was improved communication with patients and relatives and it was suggested that a further exchange of information between doctors, patients and the families was essential in promoting ethical decision-making. By enabling the patient to make an anticipatory decision regarding treatment, an advance directive could enhance his or her self-determination. Greater rights for patients admitted to NHS hospitals, including access to health records, participation in treatment decisions and full disclosure of treatment options as part of informed consent were recommended on grounds that address a major cause of dissatisfaction among hospital patients regarding communication about their condition and treatment (Morgan, 1997: 75).

Trying to protect personal autonomy may be a lost cause according to one English lawyer, who noted that other powerful professionals (such as lawyers) might lose personal autonomy when they become ill. Nonetheless, he believed that this provided greater backing for advance directives as protectors of autonomy. Other lawyers interviewed in England did not believe professional autonomy was under threat because of advance directives. Indeed a recent survey found that advance decisions do not meaningfully alter the care given to patients (Goodman *et al*, 1998: 701), this will not only be a relief to those doctors who do not wish to be bound by them, but will also cast doubt on whether they assert patients' choices at all.

Lawyers in England were more likely to be involved in disputes about medical decision-making and English case law has frequently referred to advance directives, albeit in *obiter dicta*. This may be part of the reason that the doctors interviewed seemed to be aware that advance directives were more of a protection of patients' personal autonomy than a threat to doctors' professional autonomy. English lawyers believed that discussion between the patient and the GP, and the consultant, and a

full explanation of the condition, the options available and the prognosis, were all necessary to promote patient autonomy. Although, advance directives could be a way of protecting patients' autonomy, their drafting and contents were crucial if they were to be successful. The doctor's duty of care might also be protected if the patient refused all or certain treatments and a valid, written advance directive was available to help substantiate the patient's wishes. Problems occurred when patients changed their minds at a point when it was too late to resume treatment but if the advance directive clearly expressed the patient's wishes it should be followed even if it caused problems with family members and the healthcare team.

Scottish geriatricians thought that if the patient had an understanding of the medical situation and knew what the consequences of certain decisions were, then the doctor did not have a right to impose his or her professional autonomy on the patient. Oncologists agreed that if the patient was cognitively intact, the doctor should respect his or her autonomy. Medical practitioners agreed that the patients' previously expressed wishes were important and that, in the case of many diseases, it was important to know when to stop treatment. They felt that the patients' decision about when to stop treatment, rather than that of the family or even the doctor, was often the right decision and the one that should be followed.

English neurologists and oncologists agreed that advance directives could protect patients' autonomy and rights. Doctors in elderly care medicine thought that they were helpful for terminally ill patients in allowing them to die with dignity and without compromising their personal autonomy. Although patient autonomy could be strengthened by advance directives, they needed to be taken very seriously by the family, the doctor and the patient. In particular, the doctor must be sure the patient understands what the directive requests. For this reason, they should be drafted with medical advice. The age of the directive, the state of the patient's mind at the time of writing, and any possible coercive pressures on the patient to complete a directive all caused problems for the autonomy the advance directive could afford its author.

Doctors recognised that many conflicts arose in determining the patient's capacity when advance directive was made. This was especially so in circumstances where the

patient had had previous mental health problems or intellectual disabilities. However, the act of writing an advance directive encouraged patients to open a dialogue with their doctors and promoted discussion of future treatment preferences. Doctors were happy to spend time with patients talking about treatment choices and advising patients and their families on outcomes that would help retain their autonomy in the case of future incapacity. What was important was that doctors treated the dialogue with patients and families as an exchange of ideas and avoided the comfortable mantle of paternalism that is easier than facing difficult decisions. The case of Miss B (who won her fight against her doctors' recommendations) to have her life support switched off is a good example of safe paternalism versus scary autonomy. The final word must go to Dame Butler-Sloss whose retort to Mr Francis (counsel for the hospital) says it all. Mr Francis was concerned that Miss B's doctors, who disagreed with her decision to withdraw life support, were understandably concerned to establish that she was competent because of the gravity of the decision. Dame Elizabeth replied:

You seem to be saying that if you want something and the doctors don't think it is a good idea because they want to do something else, the more you disagree the more you will be regarded as unable to make a decision. That is a dangerous concept. There is a very paternalistic element. It's a very "doctor knows best" concept. I really bridle at that as a member of the public as well as a judge (*Re B (adult: refusal of medical treatment)* [2002]).

A summary of the answers to question five is set out below.

7.6 Summary of comparisons for research question five

How do advance directives affect professional and patient autonomy and the balance of power between doctor and patient?

Question Five	<i>Netherlands</i>	<i>Scotland</i>	<i>England</i>
Professional autonomy	“Doctor knows best” Professional and individual autonomies may conflict	Doctors will override the patient’s wishes if they feel the treatment choice made by the patient is irrational	Doctors have a powerful social position intrinsic to medicine
Individual autonomy	Strengthen substituted judgement Increase patient autonomy	A move away from paternalism Could protect patients’ rights	Strengthen autonomy
Effect of advance directives on professional autonomy	Little effect, but might diminish professional autonomy slightly	Might restrict doctor’s decision-making	Might help doctor’s decision-making but could diminish autonomy
Effect of advance directives on individual autonomy	AD can be used to strengthen the patient’s substituted judgement	ADs useful in promoting the patient’s personal autonomy Safeguard sometimes necessary because of struggles between professional and personal autonomy	Unless fully informed of all available choices, then AD may fail to protect patient’s autonomy to its full extent

Discussion

In the Netherlands, statute law governs part of medical decision-making, in Scotland and England, common law doctrine governs medical law for competent patients and similar rules of informed consent as in the Netherlands apply. In Scotland statute law authorises treatment for incapacitated patients and the common law currently does the same in England. Dutch doctors interviewed stated they are more likely to use substituted judgment of the incompetent patient's wishes to make decisions on his or her behalf, while doctors in Scotland and England interviewed appear to follow the more paternalistic best interests approach.

One legal aspect of individual autonomy is that competent patients have the right to refuse medical advice or intervention - a negative declaration of will. This right may be restricted if doctors do not inform patients of their right to refuse treatment, a practice that is prevalent among the doctors interviewed in the Netherlands as well as in Scotland and England. There are assumptions made by doctors interviewed that patients do not need or even want to have certain information and a paternalistic attitude prevails which highlights a "doctor knows best attitude". There may be concerns whether the doctor whose input has been refused may be in breach of his or her duty of care. In these situations, a point may arrive in the course of the illness, when the patient can no longer make a decision and the doctor has to decide, with or without the help of an advance statement, what to do.

Although relatives are consulted in order to determine what the patient would have wanted, Scottish and English doctors asked relatives to consent to treatments on behalf of the patient. These actions reflect either a lack of knowledge of the law on medical decision-making or a disregard for it. The data does not make it clear whether statute law has any more authority than the common law in medical decision-making, but for doctors in all three jurisdictions the law is not the foremost consideration when they make treatment decisions.

In each of the three countries doctor enjoyed a position of power, respect and trust among most patients. This was felt to be most prevalent among the elderly who appeared to be happy to abdicate their own autonomy to that of their doctors and

found it hard to challenge or disagree with decisions or recommendations made on their behalf. The “doctor knows best” attitude did not help when it came to problems and challenges for doctors. Problems with the families of *incapax* patients were mentioned quite frequently by doctors and lawyers. The common factor in all these problems was lack of communication between the doctor and the patient, between the doctor and the patients’ families, and sometimes within the families.

Advance directives are still uncommon in all three countries, even in the Netherlands, and few patients have an advance directive at present. In the Netherlands they were most frequently encountered by doctors, among nursing home residents, in the UK among patients in neurology and elderly care medicine. In the Netherlands it was considered routine, by the doctors interviewed, to ask patients if they had an advance directive when they were admitted to hospital or a nursing home. In Scotland and patients were apparently never asked and several doctors stated that the onus was on the patient or on the relative to inform the doctor of the existence of an advance directive.

Advance directives are legally binding on doctors for incapacitated patients in the Netherlands by statute and in Scotland and England through case law. Lawyers interviewed in the Netherlands were aware that they were legally binding, lawyers interviewed in Scotland and England did not. In Scotland and in England most of the lawyers did not think they were legally binding although they were aware of case law and court rulings. Some doctors in the Netherlands did not believe they would be bound by an advance directive; others did not know what the legal status of advance directives was and most thought that, if there was any doubt, the doctor’s view would prevail. In Scotland only one doctor believed them to be legally binding, the remainder were only prepared to consider them. Most doctors in England and only some in Scotland were aware of the BMA guidelines and some in England and Scotland knew about the case law. Opinion was mixed concerning their binding nature and some doctors in England would overrule them if they disagreed with them, even where they were valid and binding.

If the legal status of advance directives is used as an unsophisticated method of measuring how well they might protect patient autonomy, statute law might be assumed to provide the best protection, as it clearly requires doctors to take account of them. The opinions of doctors and lawyers interviewed in the Netherlands, Scotland and England show, however, that there is little difference between statute and common law in the use of advance directives and protection of patients' autonomy, data from the interviews indicate that there are many more factors involved. These include: the doctor's beliefs in the directive's binding nature, the lawyer's advice to his/her medical client, the content of the directive, the capacity of the individual when he or she completed the advance directive, the views of the family, the efficacy of the treatment, the prognosis, etc. In reality, many other considerations in addition to what the law says are significant, and legislation for advance directives is only one aspect of this complex area.

Doctors in all three countries frequently overrule advance directives. In the Netherlands, doctors will overrule the directive if the care they are asked to refrain from is not up to professional standards. Conscientious objection to following an advance directive is allowed as long as the doctor comes to a reasonable arrangement with the patient. In Scotland, lawyers saw it as the role of the courts to decide whether an advance directive should be overruled and although the BMA and GMC have issued guidelines, there is no strict duty to follow them. An advance directive can be overruled if it is regarded as irrational and doctors can object to them on conscience grounds, for ethical or religious reasons. In England, lawyers considered that ethics or religion were not good enough reasons for conscientious objection but doctors thought that conscientious objection should be allowed. It seems that the main reason for overriding advance directives was not because they diminished professional autonomy in any way but more that the care consented to was not in the patients' best interests. This is also a paternalistic justification that does not take into consideration the true reason for having an advance directive in the first place, which is to retain patient autonomy into incapacity. It would be preferable if the doctor were to use a substituted judgement approach if there are doubts about the advance directive. While this approach is not perfect, it represents a move away from paternalism and toward respect for autonomy.

Following an advance directive that sets out a person's wishes for the future can have an effect on the doctor's decision-making. In many cases the medical practitioner will agree with what has been set out in a document by the patient and this may help in assuring the doctor that he or she is making the right decision, both clinically and in terms of the patient's wishes. Nevertheless, some doctors felt that advance directives can erode their decision-making power and this may create conflict between the physician's professional autonomy and the patient's personal autonomy. In the Netherlands, doctors interviewed felt they could get round them if necessary. In Scotland doctors consider them and follow them only if they do not go against the doctor's own decisions. In England they are influential but can be overruled if necessary.

Patients' views are held to be important by the interviewees in all three jurisdictions. Compared to doctors, lawyers in each of the three countries were aware of the conflicts that can arise between professional and personal autonomy and could see how patients' wishes can often take second place to those of medical practitioners. Professional autonomy in the Netherlands was strong and sometimes clashed with individual autonomy. In Scotland they could in theory restrict medical decision-making but doctors would (in practice) override them if they felt the patients' wishes were irrational. They could be useful in promoting patient autonomy and help in the move away from paternalism and towards protection of patient's rights. Safeguards might be necessary because of the struggles that could develop between professional and personal autonomy. In England, advance directives may help doctors make better decisions for incompetent patients but in doing so they may infringe the doctor's professional autonomy. However, unless the patient is fully informed of all the available choices, the advance directive may fail to protect patient autonomy fully.

Implications for Policy and Practice

This study has highlighted the attitudes of the main players towards advance directives. Attitudes can be altered by better communication and more open relationships between professionals and the public and between doctors and patients in particular. One conclusion, open to consideration, is that having an advance directive may not reinforce autonomy when capacity is lost, but making one may. If undertaken correctly, with discussion and advice from legal and medical professionals, an advance directive can open up a dialogue between doctors and patients, reassuring patients that their doctors are aware of what they want when the time comes and will help doctors understand what patients really want in circumstances that have been anticipated.

One factor that has been identified as extremely important for patients and families, and least often achieved, is successful communication with the medical practitioners. When communication does not take place or is inadequate, doctors may be left to determine what their patient's wishes would have been regarding end-of-life decisions. This leaves potential for conflict between the doctor and the family, as terminal patients are often incapable of participating in discussions regarding end-of-life treatment. Advance care planning on the part of the patient in terms of making their wishes known and education of healthcare professionals are essential in promoting effective communication and thereby avoiding conflict in difficult end-of-life decisions (Friedman, 2001).

In order for advance directives to become better understood by all parties, awareness-raising and education re both is necessary. The "Let Me Decide" advance directive program in the USA (Molloy *et al*, 2000), involved educating staff in local hospitals and nursing homes, residents, and families about advance directives and offering competent residents or the next-of-kin of mentally incompetent residents an advance directive that provided a range of health care choices for life-threatening illness, cardiac arrest, and artificial nutrition. A similar study conducted in the UK might produce information on advance directives that could be valuable in promoting them among the public and healthcare providers.

In more general terms, this study has shown a need for instruction in relevant aspects of law for medical practitioners and other healthcare professionals. Davidson *et al* (2004) highlighted the need for general medical practitioner training when significant pieces of legislation come into force (*ibid*, 62). Even the small sample of practitioners in that study shows that there are misconceptions and misinformation surrounding the law on consent and capacity and further guidance in these areas can only improve understanding of the legal situation. Guidance is also required in relation to the legal rules surrounding the creation and use of advance directives. It is acknowledged that making additional training a statutory requirement for medical practitioners was unheard of in the UK prior to the implementation of the Mental Health (Care and Treatment) (Scotland) Act 2003³⁹ but knowledge of the law in certain areas may need to be made compulsory for those discharging functions under any Act that contains advance directives and associated factors.

Greater communication between doctors and patients and less withholding of information should become normal practice within the medical profession. A move away from paternalism, greater acceptance of individual autonomy and joint decision-making between doctor and patient should accompany the adoption of models of decision-making for incapable adults that follow substituted judgement models rather than best interests. These attitudes are best addressed at the earliest opportunity and should therefore be part of medical students' curriculum prior to any patient contact.

At the beginning and end of it all is communication and dialogue. Kafka's story of the country doctor symbolises the experience of being a healer at any time or place. The sick are needy, vulnerable, and sometimes demanding; the physician is only human, can only accomplish so much, and is often mistaken. There may be an inevitable tension between professional goals and private life. In Kafka's words, 'writing prescriptions is easy, but communicating with folk otherwise is hard' (1916).

³⁹ Training is required by statute for psychiatrists under the 2003 Act in order for them to achieve Approved Medical Practitioner status; otherwise, they would be unable to undertake certain functions under the Act. This is the first time that any Parliament has imposed this requirement under law on doctors.

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Appendix A Interview Letters

Sample Interview Request Letter (1) – Scottish Doctors

Date

Professor XXXXX

Address

Telephone 0131 650 3920

Dear Professor XXXXX

PhD Research: Advance Directives

I am a PhD student in the Department of Social Policy currently undertaking research on advance directives and how they work in practice in Scotland, The Netherlands and England. For this comparative study I propose to interview ten doctors, and ten lawyers in each of these areas, to establish how treatment decisions are made when patients no longer have the capacity to consent or refuse, and what effects (if any) advance directives may have on this process.

My background encompasses both medical and legal spheres. I was employed as a psychiatric nurse at Stratheden Hospital, Cupar for seventeen years, ten years at Senior Charge Nurse level. On leaving the NHS, I undertook a law degree and last year successfully completed an MSc by Research in Social Policy. My dissertation examined the reasons behind the Scottish Parliament withdrawing advance directives from the Adults with Incapacity (Scotland) Act 2000, in which I interviewed pressure groups, religious organisations, civil servants, and members of the Scottish Law Commission. My PhD research builds on those findings.

Due to the restrictions of time, I have decided to confine my investigation to three areas of medicine: geriatric medicine, oncology, and neurology. My method of research would be to conduct qualitative interviews with three or four consultants in the Department of Geriatric Medicine, and likewise in the Departments of Oncology and Clinical Neurosciences. My reason for writing to you at this stage is to elicit your expertise and your permission to approach doctors within your department.

I realise that medical personnel are very busy and in order to reduce the contact time to a minimum, I wondered if you would be willing to suggest names of consultants who may be willing to help in my research, I would then approach them personally by letter. Face-to-face interviews would be conducted at their convenience, with my assurance of confidentiality and anonymity. I have already made enquiries of the Medicine/Oncology Ethics Sub-Committee, and, as no individual patient information is required, no formal application for ethical clearance is required, as this type of research is classified as "audit" only.

I would be willing to meet with you to discuss my research in greater depth, and to answer any questions you may have, meantime please be assured of my appreciation of your time and attention. I can be contacted by email or by telephone, and of course, by mail at the above address, I look forward to hearing from you.

Yours sincerely

Susan Anderson

Sample Interview Request Letter (2) – Scottish Doctors

Date

Telephone 0131 650 3920

Recipient Doctor Name
Address

Dear Dr XXXXX

Doctoral Research

Please forgive this unsolicited letter but I was given your name by Dr XXXXX, as he believes you may be able to help with my research.

I am currently doing fieldwork research on advance directives funded by the Economic Social and Research Council (ESRC). I am conducting a comparative study of the legal and medical issues surrounding decision-making for patients who have lost capacity to consent or refuse treatment in the Netherlands, Scotland and England. I am also interested in how advance directives/living wills may or may not help retain a patient's autonomy in these decision choices. I have already interviewed 10 doctors and 10 lawyers in the Netherlands to discover how treatment directives work from legal and medical points of view, whether they cause or solve legal problems, and how the two professions view them. I am now doing the same in Scotland. I understand that advance directives or living wills are relatively seldom used in Scotland as a method of treatment decision-making for persons with incapacity, but I am interested in doctors' opinions on advance directives and their impact on decision-making.

My background is in nursing and law. I was a senior nurse for 15 years before the profession to undertake a law degree, I then undertook an MSc by Research in which I investigated the reasons behind the decision of the Scottish Parliament not to include advance directives in the recent Adults with Incapacity (Scotland) Act 2000. I am now doing a PhD with the Department of Social Policy at the University of Edinburgh.

I realise that you are probably very busy, but I would appreciate any time you feel able to give and ask that you consider this request favourably. The interview should last approximately 30 – 40 minutes and, with your permission, would be tape-recorded. The interview is in two parts. Firstly, I am interested in your views on medical decision-making for incapacitated patients and how this works in practice. The second part is mainly about advance directives: how doctors view them, their status in hospitals and nursing homes and how they can protect patients' human rights.

I look forward to your reply, and I am grateful for any help you may be able to give me. I will telephone your office next week to find out your thoughts on my request or I can be contacted by email: s.j.anderson-3@sms.ed.ac.uk or by telephone and fax at the numbers below.

Yours sincerely

Susan Anderson

Sample Interview Request Letter – Scottish Lawyers

Date

Telephone 0131 650 3920

Recipient Lawyer's Name
Address

Dear Mr XXXXX

Doctoral Research

Please forgive this unsolicited letter but I hope you may be able to help with my research.

I am currently doing fieldwork research on advance directives funded by the Economic Social and Research Council (ESRC). I am conducting a comparative study of the legal and medical issues surrounding decision-making for patients who have lost capacity to consent or refuse treatment in the Netherlands, Scotland and England. I am also interested in how advance directives/living wills may or may not help retain a patient's autonomy in these decision choices. I have already interviewed 10 doctors and 10 lawyers in the Netherlands to discover how treatment directives work from legal and medical points of view, whether they cause or solve legal problems, and how the two professions view them. I am now doing the same in Scotland. I understand that advance directives or living wills are relatively seldom used in Scotland as a method of treatment decision-making for persons with incapacity, but I am interested in lawyers' opinions on the legal status of advance directives and their potentially binding nature on doctors in the decision-making process.

My background is in nursing and law. I was a senior nurse for 15 years before the profession to undertake a law degree, I then undertook an MSc by Research in which I investigated the reasons behind the decision of the Scottish Parliament not to include advance directives in the recent Adults with Incapacity (Scotland) Act 2000. I am now doing a PhD with the Department of Social Policy at the University of Edinburgh.

I realise that you are probably very busy, but I would appreciate any time you feel able to give and ask that you consider this request favourably. The interview should last approximately 30 minutes and, with your permission, would be tape-recorded. The interview is in two parts. Firstly, I am interested in your views on medical decision-making for incapacitated patients and how the law in Scotland works in practice. The second part is mainly about advance directives: how lawyers view them, their legal status and how they can protect patients' human rights.

I look forward to your reply, and I am grateful for any help you may be able to give me. I will telephone your office next week to find out your thoughts on my request or I can be contacted by email: s.j.anderson-3@sms.ed.ac.uk or by telephone and fax at the numbers below. In addition I can be contacted at home on 01592 206796. If you cannot help please feel free to pass this letter to your colleagues.

Yours sincerely

Susan Anderson

Sample Interview Request Letter – English Doctors

Date

Telephone 0131 650 3920

Recipient Doctor
Address

Dear Dr XXXXX

Doctoral Research: Advance Directives

I am a researcher in the Department of Social Policy currently undertaking a study on advance directives and how they work in practice in England, Scotland, and The Netherlands. For this comparative study I am interviewing ten doctors, and ten lawyers in each of these countries, (the Scottish and Dutch components are completed) to establish how treatment decisions are made when patients no longer have the capacity to consent or refuse, and what effects (if any) advance directives may have on this process.

Due to restrictions of time, I am confining my investigation to three areas of medicine: neurology, care of the elderly, and oncology. My method of research is to conduct qualitative interviews with three or four consultants in each of these departments. I have spoken to Dr XXXXX at the XXXXX Hospital in Edinburgh, and he has suggested that you might be willing to be interviewed in connection with my research. I realise that you are very busy and therefore the interview would be kept to 30-45 minutes at most and would be conducted at your convenience, with my assurance of confidentiality and anonymity. This research methodology has been submitted to the Medicine/Oncology Ethics Sub-Committee, at the University of Edinburgh, and, as no individual patient information is required, no formal application for ethical clearance is required, as this type of research is classified as "audit" only.

I am willing to discuss my research in greater depth, and to answer any questions you may have, meantime please be assured of my appreciation of your time and attention. I can be contacted by email or by telephone, and of course, by mail at the above address, but to keep contact time to a minimum I will contact your secretary later in the week for your decision. If you have any other suggestions for potential interviewees, I would be very grateful. Thank you for your help.

Yours sincerely

Susan Anderson

Sample Interview Request Letter – English Lawyers

Date

0131 650 3920

Recipient Name
Address

Dear

PhD Research

Please forgive this unsolicited letter but I believe you may be able to help with my research.

I am currently doing fieldwork research for my doctorate on advance directives in which I am conducting a comparative study of the use of treatment directives for patients who no longer have capacity to consent or refuse medical treatment in the Netherlands, Scotland and England. In order to find out more about this issue I have already interviewed 10 doctors and 10 lawyers in the Netherlands and in Scotland to discover how treatment directives work from legal and medical points of view, whether they cause or solve legal problems, and how the two professions view them. I am now doing the same in England. I understand that advance directives or living wills are rarely used in England as a method of treatment decision-making for persons with incapacity, but I am interested in lawyers' opinions on the legal status of advance directives and their potentially binding nature on doctors in decision-making.

My background is in nursing and law. I was a senior nurse for 15 years before the profession to undertake a law degree, I then undertook an MSc by Research in which I investigated the reasons behind the decision of the Scottish Parliament not to include advance directives in the recent Adults with Incapacity (Scotland) Act 2000. I am now doing a PhD with the Department of Social Policy at the University of Edinburgh.

I realise that you are probably very busy, but I would appreciate any time you give me and ask that you consider this request favourably. The interview would last approximately 30-40 minutes and, with your permission, would be tape-recorded. The interview is in two parts. Firstly, I am interested in your views on medical decision-making for incapacitated patients and how the law in England works in practice. The second part is mainly about advance directives: how lawyers view them, their legal status and how they can protect patients' human rights.

I look forward to your reply, and I am grateful for any help you may be able to give me. I can be contacted by email: s.j.anderson-3@sms.ed.ac.uk or by telephone and fax at the numbers above.

Yours sincerely

Susan Anderson

Sample Thank-you Letter



Date

0131 650 3920

Dr/Mr/Ms XXXX
Address

Dear

Doctoral Research

Thank you very much for granting me an interview recently. I have now completed the transcription and find your comments very helpful and informative. I have now nearly completed the Dutch/Scottish/English part of my fieldwork and ready to proceed with interviews in Scotland/England where I hope that I will have as much success with my respondents as I have encountered both here and in the Netherlands.

Please be assured that your comments will be treated with the utmost confidentiality and that you will not be referred to by name or specific locality.

Thank you again for all your help.

Yours sincerely

Susan Anderson

Appendix B Interview Schedules

Interview with Dutch Doctors

Thank you for agreeing to be interviewed and for helping me with this research. This part of my research project looks at treatment decision-making and advance directives as part of a comparative study between The Netherlands, Scotland and England for my PhD. I can assure you that your answers to the following questions will be kept confidential and that you will not be referred to by name, although you may be quoted directly. I would be grateful if you would allow me to tape record this interview as it aids greatly with transcription.

In this interview I am interested in finding out how treatment decisions are made for patients who can no longer give or withhold their consent. I am primarily looking at patients within care of the elderly, neurology (mainly 'stroke' patients) and oncology. The interview is divided into two parts: firstly, I would like to find out how these treatment decisions are made; secondly, I want to investigate what effect (if any) advance directives may have on making these decisions.

Part One – Making Decisions

1. Can you tell me a little about your job?
2. How are treatment decisions for patients with capacity made?
3. If a patient is not capable of making treatment decisions, who would make these decisions?
4. How are disagreements about treatment decisions between patients and clinicians resolved?
5. How would you determine whether a patient was capable of making decisions about his/her own treatment?
6. Who would be consulted? Relatives, friends, other clinicians, healthcare team, ethics committee?
7. How would these decisions be made? 'Substituted-judgement' (autonomy model) or 'best interests' (beneficence model)?
8. Which is the more effective method of surrogate decision-making? How is patient autonomy preserved?

9. How does the doctor's professional duty of care affect patient autonomy?
10. How would you resolve any disagreements in these consultations? Who has the last say?
11. What do healthcare workers tell patients about their right to refuse treatment?

Part Two – Advance Directives

1. What do you understand by the terms 'advance directive' or 'living will'?
2. Do you believe they are legally binding on doctors?
3. Are patients or their families asked whether they have an advance directive?
4. How widely are advance directives used? Have you had experience of treating a patient with such a treatment directive?
5. How influential are advance directives on the decision-making process?
6. Do you think that healthcare workers should be allowed to refuse to treat a patient with an advance directive because they have conscientious objections?
7. If an advance directive was appropriate and applicable in the circumstances, but the family of the person objected to it being complied with, which party would carry more weight in your ultimate decision?
8. Do you think that advance directives may have an impact on resource issues? For example, freeing up beds because patients do not want to be kept alive; refusal of medication, etc.
9. Do you think advance directives should be used more widely? Would it make your job easier?
10. Do you believe advance directives are a useful method of safeguarding a person's human rights? For example, the right to family life, right to protection from cruel and degrading treatment?
11. Do you think that advance directives should be given some sort of legislative status? Are you happy with their current status?
12. Do you agree that patients should be allowed to ask for euthanasia at a later date through an advance directive?

Thank you for your time and your assistance. Please let me assure you again that confidentiality and anonymity will be respected.

Interview with Dutch Lawyers

Thank you for agreeing to be interviewed and for helping me with this research. This part of my research project looks at the law surrounding treatment decisions-making and advance directives in the Netherlands as part of a comparative study between The Netherlands, Scotland and England for my PhD. I can assure you that your answers to the following questions will be kept confidential and that you will not be referred to by name, although you may be quoted directly. I would be grateful if you would allow me to tape record this interview as it aids greatly with transcription.

The interview is divided into two parts: firstly, I am interested in find out what the law in relation to medical decision-making and incapacity is, and how it works, in the Netherlands; the second part is concerned with how advance directives (living wills) are fit into the legislative framework and how they work in practice.

Part One – The Law

1. What type of law do you practice here in the Netherlands, and how long have you been practising?
2. The Law on Contracts for Medical Treatment (WGBO) is the Act that concerns treatment decision-making for patients able and unable to give consent. The intention of this Act was to strengthen the legal position of the patient, why do you think this was felt to be necessary?
3. Is there any case law you can tell me about in connection with this area of law?
4. Why do you think the Government chose contract law rather than self-regulation or some other civil code?
5. In your opinion, has the public become more aware of their rights to refuse treatment because of this Act, or has there been some other reason?
6. Does the Act provide the same protection for incapable adults as capable ones in treatment decision-making? If so, in what way?
7. Do you think the Act strikes the right balance between doctor and patient?
8. Are patients' rights more easily enforceable? How does this normally happen?
9. There was a last minute amendment to include written statements as part of the legislation, how valuable is this part of the Act?

10. In your experience do people look for legal advice and is there much litigation in the area of health law?
11. How do the courts view the medical profession?

Part Two – Advance Directives/Living Wills

1. Do lawyers draft living wills?
2. To the best of your knowledge how widespread is their use?
3. To what extent do you think they are legally binding on doctors?
4. In what circumstances do you think they should not be binding?
5. Do you think doctors should be able to overrule a living will? If so, in what circumstances?
6. Do you believe doctors have the right to object to treating patients with living wills because of their religious or moral beliefs? What are the alternatives for both doctor and patient?
7. What happens when the family disagrees with a patient's living will, should and do lawyers become involved in the dispute? Does this happen on a regular basis?
8. Do you think that doctors should be punished by the criminal law for overriding instructions in a living will? What are the alternative sanctions that you think might be useful?
9. How useful are advance directives in promoting patient autonomy?
10. Do you think patients should be allowed to ask for euthanasia in the future using a living will?
11. Are you happy with the law on advance directives at the present time?

Thank you for your time and your assistance. Please let me assure you again that confidentiality and anonymity will be respected.

Interview with Scottish Doctors

Thank you for agreeing to be interviewed and for helping me with this research. This part of my research project looks at treatment decision-making and advance directives as part of a comparative study between Scotland, The Netherlands and England for my PhD. I can assure you that your answers to the following questions will be kept confidential and that you will not be referred to by name, although you may be quoted directly. I would be grateful if you would allow me to tape record this interview as it aids greatly with transcription.

This project is concerned with finding out how treatment decisions are made for patients who can no longer give or withhold their consent. I am primarily looking at patients within care of the elderly, neurology (mainly 'stroke' patients) and oncology. The interview is divided into two parts: firstly, I would like to find out how these treatment decisions are made; secondly, I want to investigate what effect (if any) advance directives may have on making these decisions.

Part One – Making Decisions

1. Can you tell me a little about your job?
2. How are treatment decisions for patients with capacity made?
3. What do healthcare workers tell patients about their right to refuse treatment?
4. How are disagreements about treatment decisions between patients and clinicians resolved?
5. How would you determine whether a patient was capable of making decisions about his/her own treatment?
6. What sort of conditions would apply in making the decision that a person was *incapax*?
7. If a patient is not capable of making treatment decisions, who would make these decisions?
8. Who would be consulted? Relatives, friends, other clinicians, healthcare team?
9. How would these decisions be made? 'Substituted-judgement' or the 'best interests' test?
10. Which is the more effective method of surrogate decision-making? How is patient autonomy preserved?
11. How does the doctor's professional duty of care affect patient autonomy?

12. How would you resolve any disagreements in these consultations? Who has the final say?

Part Two – Advance Directives

1. What do you understand by the terms ‘advance directive’ or ‘living will’?
2. Do you believe they are legally binding on doctors?
3. Have you had a patient in your care with an advance directive? Do you know of any other doctors who may have had dealings with them?
4. Are patients or their families asked whether they have an advance directive?
5. If a patient had an advance directive that stated certain conditions where he or she would not consent to treatment or specified a reduction in treatment, what role would that advance directive have in the decision-making process?
6. Would the fact that a patient had an advance directive influence how decision-making was carried out?
7. It has been said that advance directives are merely a short step from voluntary euthanasia. Do you think that healthcare workers should be allowed to refuse to treat a patient with an advance directive because they have conscientious objections?
8. If an advance directive was appropriate and applicable in the circumstances, but the family of the person objected to it being complied with, which party would carry more weight in your ultimate decision?
9. Do you think that advance directives may have an impact on resource issues? For example, freeing up beds because patients do not want to be kept alive; refusal of medication, etc.
10. Do you think advance directives should be used more widely? Would it make your job easier?
11. Do you believe advance directives are a useful method of safeguarding a person’s human rights? For example, the right to family life, right to protection from cruel and degrading treatment?
12. Do you think that advance directives should be given some sort of legislative status?

Thank you for your time and your assistance. Please let me assure you again that confidentiality and anonymity will be respected.

Interview with Scottish Lawyers

Thank you for agreeing to be interviewed and for helping me with this research. This part of my research looks at the law surrounding treatment decision-making and advance directives as part of a comparative study between Scotland, the Netherlands and England for my PhD. I can assure you that your answers to the following questions will be kept confidential and that you will not be referred to by name, although you may be quoted directly. I would be grateful if you would allow me to tape record this interview as it aids greatly with transcription.

The interview is divided into two parts: firstly, I am interested in find out how lawyers view the law on decision-making for the incapacitated patient and how it works within Scotland; the second part is concerned with how advance directives (living wills) are situated within the legislative framework and how they work in practice.

Part One – The Law

1. What type of law do you practice here in Scotland, and how long have you been practising?
2. What is your view of the law surrounding medical decision-making on behalf of persons who have lost the capacity to consent or refuse medical treatment?
3. When a patient is no longer capable of making his or her own decisions, do lawyers become involved in the decision-making process?
4. In your experience, do doctors seek legal advice in circumstances of decision-making for patients who have lost capacity?
5. What about relatives and friends or the patient, do they consult lawyers for help in the decision-making process?

Part Two – Advance Directives/Living Wills

1. Do lawyers draft living wills?
2. To the best of your knowledge how widespread is their use?
3. Do you believe that they are legally binding, under common law, in Scotland, in a similar fashion to their common law status in England?

4. To what extent do you think they are legally binding on doctors?
5. Do you believe that oral advance statements have the same legal status as a written statement?
6. In what circumstances do you think they should not be binding?
7. As a practitioner, are you happy with the present legal status of advance directives/living wills? Do you think they should be enshrined in statute, or is their common law status adequate?
8. Do you think doctors should be able to overrule a living will?
9. Do you believe doctors have the right to object to treating patients with living wills because of their religious or moral beliefs?
10. What happens when the family disagrees with a patient's living will, does the lawyer become involved in the dispute?
11. Do you think that doctors should be punished by the criminal law for overriding instructions in a living will?
12. How useful do you believe advance directives can be in promoting patient autonomy?
13. Do you think living wills can help to protect a patient's human rights (especially Article 3, ECHR, protection from cruel and inhuman treatment)?
14. Do you think patients should be allowed to ask for euthanasia in the future using a living will?

Thank you for your time and your assistance. Please let me assure you again that confidentiality and anonymity will be respected.

Interview with English Doctors

Thank you for agreeing to be interviewed and for helping me with this research. This part of my research looks at the law surrounding treatment decision-making and advance directives as part of a comparative study between England, Scotland and the Netherlands for my PhD. I can assure you that your answers to the following questions will be kept confidential and that you will not be referred to by name, although you may be quoted directly. I would be grateful if you would allow me to tape record this interview as it aids greatly with transcription.

This project is concerned with finding out how treatment decisions are made for patients who can no longer give or withhold their consent. I am primarily looking at patients within care of the elderly, neurology (mainly 'stroke' patients) and oncology. The interview is divided into two parts: firstly, I would like to find out how these treatment decisions are made; secondly, I want to investigate what effect (if any) advance directives may have on making these decisions.

Part One – Making Decisions

1. Can you tell me a little about your job?
2. How are treatment decisions for patients with capacity made?
3. What do healthcare workers tell patients about their right to refuse treatment?
4. How are disagreements about treatment decisions between patients and clinicians resolved?
5. How would you determine whether a patient was capable of making decisions about his/her own treatment?
6. What sort of conditions would apply in making the decision that a person was *incapax*?
7. If a patient is not capable of making treatment decisions, who would make these decisions?
8. Who would be consulted? Relatives, friends, other clinicians, healthcare team?
9. How would these decisions be made? 'Substituted-judgement' or the 'best interests' test?
10. Which is the more effective method of surrogate decision-making? How is patient autonomy preserved?
11. How does the doctor's professional duty of care affect patient autonomy?

12. How would you resolve any disagreements in these consultations? Who has the final say?

Part Two – Advance Directives

1. What do you understand by the terms ‘advance directive’ or ‘living will’?
2. Do you believe they are legally binding on doctors?
3. Have you had a patient in your care with an advance directive? Do you know of any other doctors who may have had dealings with them?
4. Are patients or their families asked whether they have an advance directive?
5. If a patient had an advance directive that stated certain conditions where he or she would not consent to treatment or specified a reduction in treatment, what role would that advance directive have in the decision-making process?
6. Would the fact that a patient had an advance directive change how decision-making was carried out?
7. It has been said that advance directives are merely a short step from voluntary euthanasia. Do you think that healthcare workers should be allowed to refuse to treat a patient with an advance directive because they have conscientious objections?
8. If an advance directive was appropriate and applicable in the circumstances, but the family of the person objected to it being complied with, which party would carry more weight in your ultimate decision?
9. Do you think that advance directives may have an impact on resource issues? For example, freeing up beds because patients do not want to be kept alive; refusal of medication, etc.
10. Do you think advance directives should be used more widely? Would it make your job easier?
11. Do you believe advance directives are a useful method of safeguarding a person’s human rights? For example, the right to family life, right to protection from cruel and degrading treatment?
12. Do you think that advance directives should be given some sort of legislative status?

Thank you for your time and your assistance. Please let me assure you again that confidentiality and anonymity will be respected.

Interview with English Lawyers

Thank you for agreeing to be interviewed and for helping me with this research. This part of my research looks at the law surrounding treatment decision-making and advance directives as part of a comparative study between England, Scotland and the Netherlands for my PhD. I can assure you that your answers to the following questions will be kept confidential and that you will not be referred to by name, although you may be quoted directly. I would be grateful if you would allow me to tape record this interview as it aids greatly with transcription.

The interview is divided into two parts: firstly, I am interested in find out how lawyers view the law on decision-making for the incapacitated patient and how it works within England; the second part is concerned with how advance directives (living wills) are situated within the legislative framework and how they work in practice.

Part One – The Law

1. What type of law do you practice here in England, and how long have you been practising?
2. What is your view of the law surrounding medical decision-making on behalf of persons who have lost the capacity to consent or refuse medical treatment?
3. When a patient is no longer capable of making his or her own decisions, do lawyers become involved in the decision-making process?
4. In your experience, do doctors seek legal advice in circumstances of decision-making for patients who have lost capacity?
5. What about relatives and friends or the patient, do they consult lawyers for help in the decision-making process?

Part Two – Advance Directives/Living Wills

15. Do lawyers draft living wills?
16. To the best of your knowledge how widespread is their use?
17. Do you believe that they are legally binding, under common law, in Scotland, in a similar fashion to their common law status in England?
18. To what extent do you think they are legally binding on doctors?

19. Do you believe that oral advance statements have the same legal status as a written statement?
20. In what circumstances do you think they should not be binding?
21. As a practitioner, are you happy with the present legal status of advance directives/living wills? Do you think they should be enshrined in statute, or is their common law status adequate?
22. Do you think doctors should be able to overrule a living will?
23. Do you believe doctors have the right to object to treating patients with living wills because of their religious or moral beliefs?
24. What happens when the family disagrees with a patient's living will, does the lawyer become involved in the dispute?
25. Do you think that doctors should be punished by the criminal law for overriding instructions in a living will?
26. How useful do you believe advance directives can be in promoting patient autonomy?
27. Do you think living wills can help to protect a patient's human rights (especially Article 3, ECHR, protection from cruel and inhuman treatment)?
28. Do you think patients should be allowed to ask for euthanasia in the future using a living will?

Thank you for your time and your assistance. Please let me assure you again that confidentiality and anonymity will be respected.

Appendix C Data Analysis

Node Listing: Doctors

Number of Nodes: 15

C1 Doctors' Nodes Listing

	<i>tree</i>	<i>node descriptor</i>
1	(1)	/Treatment Decisions
2	(1 1)	/Treatment Decisions/Capax patients
3	(1 2)	/Treatment Decisions/Incapax patients
4	(1 3)	/Treatment Decisions/power
5	(1 4)	/Treatment Decisions/Decision-making models
6	(1 5)	/Treatment Decisions/Right to Refuse Treatment
7	(1 6)	/Treatment Decisions/Conflicts in decision-making
8	(2)	/Advance Directives
9	(2 1)	/Advance Directives/definitions
10	(2 2)	/Advance Directives/use of advance directives
11	(2 3)	/Advance Directives/hospital admission
12	(2 4)	/Advance Directives/legality
13	(2 5)	/Advance Directives/overriding advance directive
14	(2 6)	/Advance Directives/patient autonomy
15	(2 7)	/Advance Directives/CO

Doctors' Themes

Free Nodes

1. type of **medicine** practiced
2. **definition** of advance directives
3. **conscientious objection** by healthcare staff
4. effect on **resources**
5. should advance directives be used to ask for **euthanasia**

Tree Nodes

Treatment decisions

1. how treatment decisions are made for patients **with capacity**
2. how are treatment decisions made for patients **without capacity**
 - a) who is **consulted**
 - b) type of **decision-making model** used by doctor
 - i. **efficacy** of this model
 - c) how is **patient autonomy** protected
 - i. impact on doctor's **duty of care**
 - ii. **advance directives** and patient autonomy
 - iii. do advance directives safeguard **patients' human rights**
3. are patients told of their **right to refuse treatment** on admission

Conflicts in treatment decisions

4. how are disagreements about treatment decisions **resolved**
 - a) do **advance directives affect** the ultimate decision
 - b) **relatives and advance directives: influence** on this decision

Legality of advance directives

5. are patients/relatives asked they have an **advance directive on admission**
6. are advance directives **legally binding**
 - a) **change in legal status**
7. **use of advance directives**
 - a) would they help doctors' jobs if **more widely used**

Node Listing: Lawyers

Number of Nodes: 13

C2 Lawyers' Nodes Listing

	<i>tree</i>	<i>node descriptor</i>
1	(1)	/Legislation
2	(1 1)	/Legislation/background
3	(1 2)	/Legislation/type of law
4	(1 3)	/Legislation/case law
5	(1 4)	/Legislation/court involvement
6	(1 5)	/Legislation/capax patients
7	(1 6)	/Legislation/incapax patients
8	(1 7)	/Legislation/refusal of treatment
9	(2)	/Advance Directives
10	(2 1)	/Advance Directives/legal status
11	(2 2)	/Advance Directives/conflicts
12	(2 3)	/Advance Directives/overriding advance directives
12	(2 4)	/Advance Directives/patient autonomy balance of rights

Lawyers' Themes

Free Nodes

1. type of **law** practiced
2. amount of **litigation**
3. experience of **drafting**
4. how do courts view **medical profession**
5. **conscientious objection** by healthcare staff
6. should advance directives be used to ask for **euthanasia**

Tree Nodes

Medical Treatment Act

1. **Strengthen legal rights** of patients
 - a) **Case law?**
 - b) Why **contract law**
 - c) Same protection for **capable/incapable**
 - d) Last minute **amendment**
2. **Balance** between doctors and patients
 - a) rights more easily **enforceable**
 - b) patient more aware of **right to refuse** treatment

Advance Directives

3. **Legally binding** on doctors
 - a) when should **not** be **binding**
 - b) should **doctors overrule**
 - c) **criminally liable** for overriding
 - d) happy with **present legal status**
4. **Patient autonomy** useful in promoting
 - a) legal involvement in **disputes**

Appendix D Sample Advance Directives

Advance Directives from the Netherlands

The NVVE has three living wills or advance directives, each with a different legal status and highly valued in both the medical and juridical scene. The value for the owner of these documents is therefore a lot higher than his/her own words scribbled on paper. The NVVE circulates about 16,000 documents each year. Every member who orders a document gets 4 copies: one to keep for him/herself, one to give to his General Practitioner, two to give to people who, by proxy, can handle his/her affairs in case s/he loses capacity to do so. More copies may be ordered if necessary.

Do Not Resuscitate Document

This document comes in a small format, like a credit card. It states that under all circumstances the owner forbids every form of resuscitation. The photograph, signature, name and date of birth of the owner are printed in an irremovable, unchangeable way so that no doubts about the identity of the card can arise by ambulance personnel or healthcare workers. The owner is advised to carry this document in an “easy to find” place, such as a wallet or diary. In addition to this card, s/he can wear a special necklace stating, “do not resuscitate”. As this necklace can not carry a signature, it is not a legally valid document, but its value is given in the fact that it always will be found and signposts the authorities to the official document.

Although this document finds its origin in the WGBO, there is some resistance especially from ambulance personnel as they claim that they are there to rescue people. As this document was only released October 1997, there has not been a prosecution yet against any ambulance personnel or doctors who neglected these documents.

Refusal of Treatment Document

In 1995 informed consent finally was recognised in Dutch law: the WGBO (the Law on Contracts for Medical Treatment). In this law, the juridical foundation of the relationship between doctors (and other people who are allowed to act medically) and patients is outlined. It is written that an informed consent is necessary for all radical treatments. The Act also states that a written refusal of treatment is equally valid as an oral refusal. Therefore, the NVVE's refusals of treatment documents have a firm juridical basis.

In this document, the owner forbids any treatment other than that based solely upon pain relief if s/he happens to become so ill that no return to a dignified life can be expected, the owner's ideas of "dignified life" will then follow. The doctor is warned that if the document is ignored, juridical action might be taken by, by the owner of the document or other authorised people. The owner again signs to show s/he is aware of the risks this document involves; if s/he changes his mind and neglects to revoke the statements back, he may risk not being treated in certain circumstances.

This document has a supplementary section (signed separately to become valid), which states, regardless of the medical expectations, the owner refuses all further treatment other than that solely based upon pain relief. The owner states that s/he regards his/her life as complete and that he forbids medical interventions to prolong life and would like to die a natural way.

Euthanasia declaration

In this document, the owner asks his doctor for a gentle, quick death if the time comes in which there is no expectation of a return to a dignified state of living. The owner of the document then describes his/her idea of a dignified state of living. There are many alternative statements for this that may be ticked and signed for, and in addition to this there is room for personal statements.

The document warns the owner, that by signing the paper s/he accepts the risk that if s/he changes his mind about euthanasia and neglects to revoke all the documents, euthanasia might be performed against his/her then current wishes. In fact, this is a theoretical danger; doctors will only perform euthanasia if the person can confirm his

wishes, either orally or writing, at the time it will be performed. Both legal and medical experts have worked on this document to ensure there is no danger of misinterpretation.

Copies of living wills are now only available to NVVE members, samples are no longer available from the NVVE website.

Advance Directives from Scotland

EXIT Living Will

Advance directives or living wills can be obtained from the voluntary euthanasia society in Scotland, EXIT, or a copy of their advance directive can be downloaded from their website. This is a comprehensive document which comes with extensive guidance notes on their use and storage.

A sample copy of the EXIT living will is attached and guidance notes are inserted.

FATE Living Will

FATE (Friends at the End) is a society established to promote knowledge about end-of-life choices and dignified death; to support those suffering from distress, especially that associated with the end of life; to advance medical education relevant to the processes of death and terminal illnesses; to fund research into the causes, cures and prevention of distress in the dying and those caring for them and to publicly disseminate the outcome of such research.

Copies of two sample living wills are inserted.

Private Solicitor's Welfare Attorney Certificate and Advance Statement

Several firms of solicitors are currently offering clients a combination of services: appointment of a Welfare Attorney (to make decisions and arrangements on their physical welfare and well being); an advance statement; and a testamentary will.

A sample copy of an appointment of a welfare attorney and an advance statement is inserted.

Important:

Living Will

This document should be lodged with the declarant's medical records.

A doctor having conscientious objection should immediately refer the declarant to another doctor. Living wills are accepted in the British Medical Association's ethical recommendations and by common law. The form does not ask the doctor to do anything illegal.

Duplicate copies may optionally be lodged with a solicitor and a close friend, and a further copy kept for reference.

Section A. ADVANCE MEDICAL DIRECTIVE. *Note: This section may be legally binding.*

Section A comprises specific instructions to the health-care team in the event that I can no longer express my own wishes; it covers very serious conditions.

To the Declarant: When filling out this part of the form, you should cross out anything that does not express your true wishes, then initial any changes clearly.

Section B. LIFE VALUES STATEMENT.

This gives indications of the personal value I attach to my life under various circumstances. I ask my health care team to bear these in mind when making difficult decisions about my treatment or non-treatment, especially in situations not covered by Section A. Where I have indicated that life under such circumstances would be "Much Worse Than Death" this means that I would find the situation totally unbearable and unacceptable, and that I would prefer all life-sustaining treatment to be stopped or withdrawn rather than exist for the rest of my life in such a state.

Note: A doctor should not be liable to civil or criminal proceedings if he acts in good faith and with reasonable care in respecting the directives and values in this document.

DO NOT FILL OUT THIS FORM WITHOUT DEEP AND CAREFUL CONSIDERATION.

Complete Section A or Section B or both.

For further information and advice on living wills, you may wish to consult your doctor or one of the organisations or individuals listed below:

Age Concern England, Astral House, 1268 London Rd, London SW16 4ER;

Phyllis Goodheir, 16 Woodlands Drive, Coatbridge, ML5 1LE;

The Natural Death Centre, 20 Heber Rd, London NW2;

The Terrence Higgins Trust, 52-54 Gray's Inn Rd, London WC1X 8JU;

The Voluntary Euthanasia Society, 13 Prince of Wales Terrace, London W8 5PG;

The Voluntary Euthanasia Society of Scotland, 17 Hart St, Edinburgh EH1 3RN.

Solicitors in England may wish to contact The Law Society, Law Society House, 50/52 Chancery Lane, London WC2A.

Physicians may wish to contact The British Medical Association, Ethics Department, BMA House, Tavistock Square, London WC1H 9JP, and consult their code of practice, "Advance Statements about Medical Treatment".

This living will form was developed by CG Docker and is © 1994, revised 1996. Requests for reprinting are welcomed however, together with suggestions for further development which should be addressed to CG Docker, BM 718, London WC1N 3XX U.K. Much of the text is drawn from existing documents, and many individuals and organisations have contributed ideas and made helpful suggestions, including the National Agency for Welfare and Health Helsinki and the Ethics Committee of the Seattle Veterans Affairs Medical Center.

Personal copies may be made by the Declarant for his or her own use.

SECTION A. ADVANCE MEDICAL DIRECTIVE

TO MY PHYSICIAN AND HEALTH CARE TEAM, MY FAMILY, MY SOLICITOR AND ALL OTHER PERSONS CONCERNED:

this declaration is made at a time when I am of sound mind and after careful consideration.

I UNDERSTAND THAT MY LIFE MAY BE SHORTENED BY THE SPECIFIC REFUSALS OF TREATMENT MADE IN THIS DOCUMENT.

I DECLARE that if at any time the following circumstances exist, namely:

(1) I suffer from one or more of the conditions mentioned in the *Schedule*; and (2) I have become unable to participate effectively in decisions about my medical care; and

(3) two independent physicians (one a consultant) are of the expert, considered opinion, after full examination of my case, that I am unlikely to make a substantial recovery from illness or impairment involving severe distress or incapacity for rational existence,

THEN AND IN THOSE CIRCUMSTANCES my directions are as follows:

1. that I am not to be subjected to any medical intervention or treatment (aimed at prolonging my life) such as life support systems, artificial ventilation, antibiotics (i.e. to control infection), artificial feeding - whether enteral or parenteral (tube feeding into the stomach or into a vein), invasive surgery, dialysis (e.g. using a kidney machine), or blood transfusion;

2. that any distressing symptoms (including any caused by lack of food or fluid) are to be fully and aggressively controlled by appropriate palliative care, ordinary nursing care, analgesic or other treatments, even though some of these treatments may have the secondary effect of shortening my life.

HOWEVER, modes of treatment mentioned in (1) above may be applied for elimination of serious symptoms. Giving intensive care to me is to be allowed only on the condition that reliable reasons exist for the possibility that such treatment will have a better result than merely short prolongation of life. In the event that a treatment with prospect of recovery has been started but proves to be futile, it has to be discontinued immediately.

I consent to anything proposed to be done or omitted in compliance with the directions expressed above and absolve my medical attendants from any civil liability arising out of such acts or omissions.

I offer the health-care team my heartfelt thanks for respecting my sincerely held wishes, as expressed in this directive.

I accept the risk that I may be unable to express a change of mind at a time in the future when I am incapacitated, that improving medical technology may offer increased hope, but I personally consider the risk of unwanted treatment to be a greater risk. **I wish it to be understood that I fear degradation and indignity far more than death.** I ask my medical attendants to bear this statement in mind when considering what my intentions would be in any uncertain situation.

I RESERVE THE RIGHT TO REVOKE THIS DIRECTIVE at any time, orally or in writing, but unless I do so it should be taken to represent my continuing directions. I hereby deliberately *accept the risk* that I may no longer be able to revoke my declaration if I am in a condition listed in the Schedule, in order to exclude a risk which is greater to me, namely that I should continue living in circumstances that are not acceptable to me.

SCHEDULE

- A Advanced disseminated malignant disease (*e.g. cancer that has spread considerably*)
- B Severe immune deficiency (*e.g. Acquired Immune Deficiency Syndrome*)
- C Advanced degenerative disease of the nervous system (*e.g advanced Parkinson's Disease*)
- D Severe and lasting brain damage due to injury, stroke, disease or other cause
- E Advanced dementia, whether Alzheimer's, multi-infarct or other, resulting in very limited awareness of the immediate environment and inability to initiate simple tasks
- F Any other condition of comparable gravity

Additional instructions (if any, such as pregnancy waiver)

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If you would like a particular person's wishes to be taken into consideration during decisions about your medical care, please give their details here:

Name of my proxy Telephone number

Address

To my proxy: Please try to ensure that decisions are taken

- (mark one box only) ☐ how you believe I would have taken them
- ☐ using your own best judgement

The wishes of your proxy may be taken into consideration, but have no overriding force in British law - neither do the wishes of relatives. It is advisable to discuss this document with your proxy.

I have discussed this document with my doctor ☐ Mark here if Yes

Doctor's Tel. No Name of Doctor

Address

It is not obligatory to discuss your living will in advance with your doctor, but it may be very helpful to do so.

SECTION B. VALUES HISTORY STATEMENT Please use this section as a guide to my values when considering the likely result of treatment.

Circle the number on the scale of one to five, that most closely indicates your feelings about each of the situations described.

Much Worse Than Death: I Would Definitely Not Want Life Sustaining Treatment	Somewhat Worse Than Death: I Would Probably Not Want Life Sustaining Treatment	Neither Better Nor Worse Than Death: I'm Not Sure Whether I Want Life- Sustaining Treatment	Somewhat Better Than Death: I Would Probably Want Life- Sustaining Treatment	Much Better Than Death: I Would Definitely Want Life- Sustaining Treatment
--	--	---	---	--

(a) Permanently paralysed. You are unable to walk but can move around in a wheelchair. You can talk and interact with other people.

1 2 3 4 5

(b) Permanently unable to speak meaningfully. You are unable to speak to others. You can walk on your own, feed yourself and take care of daily needs such as bathing and dressing yourself.

1 2 3 4 5

(c) Permanently unable to care for yourself. You are bedridden, unable to wash, feed, or dress yourself. You are totally cared for by others.

1 2 3 4 5

(d) Permanently in pain. You are in severe bodily pain that cannot be totally controlled or completely eliminated by medications.

1 2 3 4 5

(e) Permanently mildly demented. You often cannot remember things, such as where you are, nor reason clearly. You are capable of speaking, but not capable of remembering the conversations; you are capable of washing, feeding and dressing yourself and are in no pain.

1 2 3 4 5

(f) Being in a short term coma. You have suffered brain damage and are not conscious and are not aware of your environment in any way. You cannot feel pain. You are cared for by others. These mental impairments may be reversed in about one week leaving mild forgetfulness and loss of memory as a consequence.

1 2 3 4 5

SIGNATURE OF DECLARANT to Sections A & B:

Name (print clearly) **Day/Month/Year**

Address.

Date of Birth*

**If you are under 18 years of age, you may still complete this document, though it may not have the same legal force.*

WITNESS'S SIGNATURE: I declare that the abovenamed has signed this document in my presence. He/she has declared it to be his/her firm will, is in full capacity and fully understands the meaning of it. I believe it to be a firm and competent statement of his/her wishes. As far as I am aware, no pressure has been brought to bear on him/her to sign such a document and I believe it to be his/her own free and considered wish. So far as I am aware, I do not stand to gain from his/her death.

Signed (Witness): **Name**

Address

SOME GUIDANCE NOTES ON COMPLETING YOUR LIVING WILL

(These notes do not form part of the living will document)

NOTE: *If you are admitted to hospital with a serious illness you are strongly advised to ask for your living will so that you can review it, update it, or affirm that it still represents your current wishes.*

Examples of Additional Instructions

It is not necessary generally to insert any additional instructions on your living will, but the following are exceptions that certain people may wish to consider. If you are adding any wording in the "additional instructions" section, it is advisable to discuss it thoroughly with a doctor first.

Example 1: Dementia declaration.

Your living will already recognizes the extreme forms of senile dementia - situations where you do not recognize your nearest relations, no longer know the time in which you live, and are no longer capable of performing the activities of daily life such as eating, drinking, washing, going to the toilet. If you also want to emphasise that you refuse treatment in the *initial* phase of senile dementia, which is characterised by periods of extreme confusion, interspersed with periods of extreme lucidity, you can add: "In the event that I find myself in the situation of the beginning of senile dementia and also have a life-threatening physical condition, I refuse all further life-sustaining treatment."

Example 2: Declaration of non-resuscitation.

One of the natural ways by which a lasting suffering can be ended is a cardiac arrest. A person to whom this happens is unconscious immediately. If no immediate action is taken, the patient will die within a short time, dying a fairly mild death. When a cardiac arrest occurs however, health care teams would generally make attempts to resuscitate the patient as soon as possible. These can take the form of heart massage, mouth-to-mouth resuscitation, or more sophisticated measures.

Resuscitation however is undesirable if you consider cardiac arrest as a relief or if in view of your age or medical condition consider the chances of complete recovery after resuscitation to be very small. Your doctor should be able to give you information about the eventual consequences of resuscitation in your situation.

If you do not want resuscitation, you will have to talk this over in good time with your doctor, your family, social workers or those close to you. You will have to consider very carefully if your wish for non-resuscitation applies to all circumstances. The following text, which also includes accident and drowning, could be added to your living will for non-resuscitation, but should *only* be included after discussion with your doctor: "I refuse all life-sustaining treatment in case I find myself in a situation of unconsciousness caused by cardiac arrest, accident or drowning. I also refuse any draining of my stomach."

Example 3: **Pregnancy waiver/non-waiver.**

If you are a woman of child-bearing age, you may wish to consider whether your wishes about non treatment should apply if you were carrying a viable foetus. You could then add one of the following texts:

a) "This living will is to be temporarily overruled if I am pregnant and, to a reasonable degree of medical certainty, the foetus may develop to the point of live birth."

OR

b) "My advance refusal of treatment, as stated in this document, is to be carried out even if I am pregnant and carrying a viable foetus, and even if this means that the foetus will not develop to the point of a live birth."

Example 4: **Refusal of specific treatments.**

If you have a condition such as AIDS or multiple sclerosis, where the prognosis involving incapacity is known with some certainty, as are the available treatment options: you may wish to make advance refusals of specific treatments, such as chemotherapy, where there is likely to be a choice between benefits and burdens. If this is the case, suitable wording should be devised with your doctor and added to your living will.

WHAT TO SAY TO YOUR DOCTOR

When you approach your doctor or medical consultant in order to lodge your living will in your medical records, you may be unsure as to his or her reaction. If your doctor has not come across a living will before, he or she may need some reassurance from you as to what it is. Bear the following points in mind, or take a photocopy of the following paragraph with you:

(You could say...) *"The purpose of the living will document is to minimize the indignity or suffering that might ensue in the event of certain irreversible conditions, and to spare doctors and relatives the problem of trying to make difficult decisions on my behalf. "*

It does not ask the doctor or nurse to do anything contrary to existing law - in fact the law fully upholds the right of any patient to decline treatment, including life-sustaining treatment, and to receive analgesic drugs in quantities to relieve intolerable distress.

If the doctor has personal objections to accepting the document or making its existence known at such times as may be appropriate, then an alternative doctor should be recommended who may not have the same reservations.

If at all possible, it is extremely desirable to discuss the living will with your doctor. Ask for the medical terms and the implications of refusing treatment to be explained so that you fully understand what you are signing. This will also mean that your doctor will be more fully aware of your wishes if he or she has to make difficult decisions at a time when you are no longer able to speak for yourself.

If you still have further queries about your living will, you can send a large stamped addressed envelope and small donation to VESS, 17 Hart St, Edinburgh EH1 3RN (UK) requesting a LIVING WILL INFORMATION PACK which provides further answers to common questions, as well as guidance on some of the difficult areas of law and medical ethics concerning such documents. Members of VESS can also obtain Living Will stickers for medical files, a document carrying case, a medical alert card to carry in a wallet, and update stickers to indicate that the document has been renewed every few years. Subscription to VESS costs £15 per year (Overseas residents: £30) and includes a regular and comprehensive newsletter, which keeps you informed of any changes in the law or practice of living wills.

Important Notes

To the maker of this *Living Will*

This is an important document. It is an Advance Directive about how you wish to be treated should you suffer a loss of mental capacity to make decisions about your future medical treatment. Please complete it clearly. You should discuss your *Living Will* with your doctor and with those who are closest to you so they are aware of your wishes.

To treating doctors

This *Living Will* is the below named person's Advance Directive which sets out his/her decision(s) to accept/refuse certain forms of medical treatment should he/she lose the capacity to consent, or lose the ability effectively to communicate his/her consent to, or refusal of, medical treatment.

This *Living Will* should be brought to the attention of all treating clinicians and nurses.

This *Living Will* was signed at a time when the person named below had the necessary capacity to consent to or refuse the treatments here described.

Knowingly to treat the person named below contrary to a clearly expressed advance refusal set out in this *Living Will* is likely to be a criminal assault.

If you are in any doubt as to the binding nature of the decisions set out in this *Living Will* you should seek independent legal advice.

Living Wills are recognised as being legally enforceable by:

- ❖ the General Medical Council
- ❖ the British Medical Association
- ❖ the Royal College of Nursing
- ❖ the Nursing and Midwifery Council
- ❖ the Law Society of England and Wales

TEXT OF LIVING WILL

Personal Details

I, name

of address

am of sound mind and not suffering from any physical or mental condition which impairs my capacity to make the medical treatment decision(s) set out in this document.

I have carefully considered how I would wish to be treated if through accident, illness, or injury I lose the capacity to consent to medical treatment or the ability effectively to communicate my consent or refusal.

A
Imminently life threatening physical illness
from which there is little or no prospect of
recovery

(please tick the box you wish to apply)

I, name

☐

(i) I wish to be kept alive for as long as reasonably possible and consent to all appropriate medical treatment.

or

☐

(ii) I refuse medical treatment aimed at prolonging or artificially sustaining my life. I consent only to medical treatment whose aim is to keep me comfortable and, so far as possible, free from pain. I refuse all other medical treatment.

declare that my medical treatment wishes are as follows:

If I suffer from physical injury or illness which in the opinion of two or more independent doctors (one a consultant), is imminently life threatening and from which there is less than a ten per cent likelihood of recovery.

Examples of an imminently life threatening condition are the last stages of MND, AIDS, extensive stroke, severe head injury, or widespread cancer where the incapacity is due to physical reasons. Please note this list is not exhaustive and is for illustrative purposes only.

B
Very serious mental impairment with no prospect of recovery together with a physical need for life sustaining treatment

I, name _____

declare that my medical treatment wishes are as follows:

If my mental functions are very seriously impaired, and (i) the impairment is so severe that I do not understand what is happening to me, and (ii) in the opinion of two independent doctors (one a consultant), there is less than a ten per cent likelihood of significant improvement, **and** (iii) my physical condition is such that medical treatment is required to keep me alive:

(Please tick the box you wish to apply)

- ☐ (i) I wish to be kept alive for as long as reasonably possible and consent to all appropriate medical treatment
- or
- ☐ (ii) I refuse medical treatment aimed at prolonging or artificially sustaining my life. I consent only to medical treatment whose aim is to keep me comfortable, and so far as possible, free from pain. I refuse all other medical treatment.

Examples of a very serious mental impairment are persistent vegetative state, very severe damage to the nervous system, or Alzheimer's disease. Please note this list is not exhaustive and is for illustrative purposes only.

In respect of specific treatment	I have been told that I have been diagnosed as suffering from	I refuse the following specific treatments for my condition
	_____	_____
	_____	_____
	_____	_____
	_____	_____
	_____	_____
	_____	_____
	_____	_____
	_____	_____
	_____	_____
	I have the following wishes about specific medical treatment or investigations	

		(If necessary, a covering letter can be written by you to expand on this section)

Refusal of treatment	I, name	I do not wish to suffer the loss of dignity which will be caused if medical treatment is given to me to which I do not consent.

		I ask my medical attendants and any person consulted by them to bear this statement in mind when considering what my intentions would be in any uncertain situations.
		I ask that any distressing symptoms caused by my refusal of treatment shall be fully controlled by appropriate palliative care, ordinary nursing care, analgesic and other treatments, even if some of these treatments may have the effect of shortening my life.
	have made a decision to refuse medical treatment in the circumstances set out in this Living Will.	
	I wish it to be understood by those treating me (and others) that my refusal of medical treatment in these circumstances is a considered and careful decision made while I have the capacity to consent to or refuse such treatment.	
	I am fully aware that one of the consequences of my refusal to accept medical treatment in these circumstances may be my death.	

Welfare Attorney

(In Scotland, all Welfare Powers of Attorney must be drawn up by a lawyer, signed and witnessed as a full legal document. You may appoint an adult as your Welfare Attorney to act for you legally in all decisions concerning your health and welfare if you become unable to make decisions for yourself.)

The following person has been appointed my Welfare Attorney to take part in discussions about my medical care on my behalf if I am unable to make my wishes known for myself. I have discussed my views about my future medical treatment with him/her and given him/her a copy of this document. This person is to be consulted about and involved in those decisions by the health care team when considering what my intentions would have been in any uncertain situation. I require anyone who is caring for me to respect the views expressed by my Welfare Attorney on my behalf.

Name _____

Address _____

Daytime telephone number _____

Evening telephone number _____
_____**Health Care Proxy**

In the event of my not having a Welfare Attorney who is able to give instructions, or in the event of that person not being available, I have asked the following person to take part in discussions about my medical care on my behalf if I am unable to make my wishes known for myself. I have discussed my views about my future medical treatment with him/her and given him/her a copy of this document. I would like this person to be consulted about and involved in those decisions by the health care team when considering what my intentions would have been in any uncertain situation. I want anyone who is caring for me to respect the views expressed by my Health Care Proxy on my behalf.

Name _____

Address _____

Daytime telephone number _____

Evening telephone number _____
_____**Presence of relative or friend**

If my life is in imminent danger I wish the following person to be contacted to give him/her the chance to be with me. I accept that it may not be possible to contact the person named and for him/her to arrive in time

Name _____

Address _____

Daytime telephone number _____

Evening telephone number _____
_____**GP details (optional)**My General Practitioner is _____
_____GP's address _____

_____GP's telephone number _____
_____**GP's declaration**

I have discussed the matters contained in this *Living Will* with _____

I am satisfied that he/she has the capacity to make the decisions contained in this document and satisfied that he/she understands the consequences of those decisions.

GP's signature _____

Date of signature _____

Signatures

In Scotland the Living Will should be witnessed by a witness who should not be a relative, your Welfare Attorney, your Health Care Proxy or anyone who stands to gain from your death. They should sign at the same time as yourself and should then print their name and address in the spaces provided.

If this deed is granted in or to be used in England and Wales a second witness is required. They should sign at the same time as yourself, and write 'witness' after their signature, and should then print their name and address in the spaces provided.

My signature

Signed

Date

Witness one

Signature

Full name of witness

Address of witness

Witness two

Signature

Full name of witness

Address of witness

Where to deposit your completed Living Will

I have given copies of this Living Will to:

AName *e.g. your GP*

Address

Telephone

BName *e.g. Welfare Attorney*

Address

Telephone number

CName any other person, *e.g. your solicitor or Health Care Proxy*

Address

Telephone

DName *e.g. your local hospital*

Address

Telephone number

Review dates

This *Living Will* was reviewed and confirmed by me as not requiring any change on the following dates:

Date

Signature

Date

Signature

Date

Signature


Date

Signature

Date

Signature

This document remains effective unless I have made it clear above that my wishes have changed and that a new version has superseded it.

Friends at the End 

11 Westbourne Gardens Glasgow G12 9XD
 website: www.friends-at-the-end.org.uk
 e-mail: info@friends-at-the-end.org.uk
 Tel + Fax: 0141 334 3287

APPENDIX 3 EXAMPLES OF LIVING WILLS - B

LIVING WILL ALLOWING FOR REFUSAL OF UNWANTED TREATMENT

TO MY FAMILY, MY PHYSICIAN AND MY SOLICITOR

This declaration is made by me, _____ residing at _____
at a time when I am of sound mind and after careful consideration.

I, the said _____

in the event of my being unable to take part in decisions concerning my medical care due to my physical or mental incapacity, and in the event that I develop one or more of the medical conditions listed in clause (3) below and in the event that two independent physicians conclude that there is no reasonable prospect of my making a substantial recovery, do hereby DECLARE that my wishes are as follows, viz:-

- (1) I request that my life should not be sustained by artificial means such as life support systems, intravenous fluids and/or drugs or tube feeding.
- (2) I request that distressing symptoms caused either by illness or by lack of food or fluid should be controlled by appropriate sedative treatment, even though such treatment may have the incidental and secondary effect of shortening my life.
- (3) The said medical conditions are:-
 1. Severe and lasting brain damage sustained as a result of an accident or injury.
 2. Advanced disseminated malignant disease.
 3. Advanced degenerative disease of the nervous and/or muscular systems with severe limitations of independent mobility, and no satisfactory response to treatment.
 4. Stroke with extensive persisting paralysis.
 5. Pre-senile, senile or Alzheimer type dementia.
 6. Other conditions of comparable gravity.
- (4) I request that, in the event of my becoming incapable of giving or withholding consent to any medical treatment or procedures proposed to me, the Court be petitioned to appoint as my Welfare Guardian,
residing at _____
whom failing _____
residing at _____
whom again failing _____
whom all failing _____

such other person as may be deemed by the Court to be a fit person. It is my specific request that in exercising his or her powers to consent or withhold consent on my behalf to any medical treatment or procedures, my guardian shall take into account, in any determination of what is in my best interests, the requests which I solemnly make in clauses (1) and (2) of this document.

And I declare that I hereby absolve my medical attendants of all legal liability arising from action taken in response to and in terms of this declaration.

I reserve the right to revoke this declaration at any time, before a witness, in writing or orally.

SIGNED by me at
on the
day of
Two thousand
in the presence of:-

Witness

Full Name

Address

(In Scotland only one witness is required)

I, _____ of _____ HEREBY APPOINT _____ of _____ as my Welfare Attorney in the event of my being incapable by reason of mental disorder or inability to communicate because of physical disability as defined in Section 1(6) of the Adults with Incapacity (Scotland) Act 2000 to make decisions and arrangements about my physical welfare and well being which I could have done myself and in particular but without prejudice to the said generality decisions and arrangements regarding

- My accommodation
- Medical, dental and optical treatment
- Alternative and complementary medical treatments
- Home care and residential and nursing home care
- Respite care
- Attendance at day care centres, lunch clubs or similar

IN WITNESS WHEREOF these presents are executed as follows:

THEY ARE SUBSCRIBED by me the said _____ at _____ on the _____ day of _____ Two thousand and one before this witness:-

Signature _____ Witness _____

Full Name _____

Address _____

Occupation _____

This certificate is incorporated in the document subscribed by _____ (the "granter") on _____ that confers a Welfare Power of Attorney on _____

I certify that:

I interviewed the granter on _____ immediately before he subscribed this Welfare Power of Attorney

AND

I am satisfied that, at the time this Welfare Power of Attorney was granted, the granter understood its nature and extent.

I have satisfied myself of this:

- (a) because of my own knowledge of the granter;
- (b) because I have consulted the following persons, who have knowledge of the granter on the matter:

(b) because I have consulted the following persons, who have knowledge of the granter on the matter:

AND

I have no reason to believe that the granter was acting under undue influence or that any other factor vitiates the granting of this Welfare Power of Attorney

.....SignatureDate

.....Name

This is the Schedule containing Advance Statement referred to in the foregoing Power of Attorney by in favour of .

In the event that I develop one or more of the medical conditions listed in Clause 3 below and that two independent Medical Practitioners conclude that there is no reasonable prospect of my recovering to be able to lead an independent existence my wishes are as follows:-

1. I do not wish my life to be artificially prolonged or sustained by the use of life support systems, intravenous fluids, intravenous drugs or tube feeding or other treatment. I accept that the consequence of withholding treatment could be premature death.
2. I understand that I cannot refuse treatment or care where this would be a risk to the physical or mental well-being of others. Where treatment or care is necessary I request I be given the minimum treatment or care to control my symptoms. I fully accept that such treatment or care may have the effect of shortening my life or causing premature death.

Without prejudice to the foregoing generality, I do not wish my life to be continued or prolonged artificially by the application of medical or other procedures, treatment with drugs or other remedies if I have one or more of the conditions listed in Clause 3 below and two independent Medical Practitioners conclude there is no reasonable prospect of my recovering to lead an independent existence.

3. The conditions referred to above are:-
 - (i) Severe and lasting brain damage sustained as a result of accident, injury or disease.
 - (ii) Advanced disseminated malignant disease.
 - (iii) Advanced degenerative disease of the nervous or muscular systems which severely limits independent mobility and does not respond to treatment.

- (iv) Extensive persisting paralysis caused by a stroke, injurious accident or otherwise
 - (v) Pre-senile, senile Alzheimer or other type of dementia.
 - (vi) Advanced HIV or other immuno deficiency
 - (vii) Other conditions of an equal or more severe gravity than the foregoing conditions which prevent my being able to lead an independent existence.
4. My Welfare Attorney must be present at all discussions of my treatment and welfare where decisions are made relating to my care and treatment. In exercising his or her powers to consent or withhold consent on my behalf to any medical treatment or procedures my Welfare Attorney shall strictly construe my best interests in accordance with my wishes contained in this advance statement. For the avoidance of doubt my best interests will be served by respecting my autonomy and not artificially prolonging my life in the situations herein anticipated.
 5. Provided my wishes herein expressed, and the wishes expressed by my Welfare Attorney, are followed I absolve my Medical Attendants of all legal liability arising from professional treatment or care given or withheld in accordance with this statement.
 6. This statement may be revoked by me at any time, before witnesses, in writing or orally:

Advance Directives from England

VES Living Will

The Voluntary Euthanasia Society (VES) supplies living wills throughout the UK. They offer a *pro-choice* living will which is endorsed by Mo Mowlam MP. It costs £15.00 for four forms, guidance notes and a medical emergency card. It is *pro-choice* because it lets the person either refuse treatment or ask for life sustaining treatment.

The *pro-choice* Living Will informs medical staff how the person wishes to be treated if he or she is no longer able to communicate his or her wishes to the medical team. The VES states that,

with the *pro-choice* Living Will you decide what happens if you are seriously ill with little chance of recovery. It makes sure it is not left to your next of kin to make life and death decisions on your behalf (VES, 2004).

A copy of the information on *pro-choice* living wills is inserted.

An older version of the VES living will was available for downloading from their website, a sample copy of this living will and instructions on how to complete it are inserted.